

# Social and Financial Outcomes of Living Liver Donation: A Prospective Investigation Within the Adult-to-Adult Living Donor Liver Transplantation Cohort Study 2 (A2ALL-2)

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Because results from single-center (mostly kidney) donor studies demonstrate interpersonal relationship and financial strains for some donors, we conducted a liver donor study involving nine centers within the Adult-to-Adult Living Donor Liver Transplantation Cohort Study 2 (A2ALL-2) consortium. Among other initiatives, A2ALL-2 examined the nature of these outcomes following donation. Using validated measures, donors were prospectively surveyed before donation and at 3, 6, 12, and 24 mo after donation. Repeated-measures regression models were used to examine social relationship and financial outcomes over time and to identify relevant predictors. Of 297 eligible donors, 271 (91%) consented and were interviewed at least once. Relationship changes were positive overall across postdonation time points, with nearly one-third reporting improved donor family and spousal or partner relationships and >50% reporting improved recipient relationships. The majority of donors, however, reported cumulative out-of-pocket medical and nonmedical expenses, which were judged burdensome by 44% of donors. Lower income predicted burdensome donation costs. Those who anticipated financial concerns and who held nonprofessional positions before donation were more likely to experience adverse financial outcomes. These data support the need for initiatives to reduce financial burden.

**Abbreviations:** A2ALL-2, Adult-to-Adult Living Donor Liver Transplantation Cohort Study 2; CI, confidence interval; IQR, interquartile range; NA, not applicable; NLDAC, National Living Donor Assistance Center; OR, odds ratio; PHQ-9, Patient Health Questionnaire 9; SD, standard deviation

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## Introduction

The increasing need to consider living liver donation as a more expeditious and certain alternative to deceased

donor transplantation necessitates ongoing efforts to maximize donor well-being. Beyond commonly considered generic quality of life (often focused on donors' physical and psychological well-being), the impact of donation on the larger context of donors' interpersonal lives, relationships and need for adequate social and financial resources before donation has been considered less often. Social and financial circumstances are important interrelated areas, especially given their potential for reciprocal influence. Donation-related financial strains, for example, may strain family, spouse or partner, and/or recipient relationships within a donor's social support network. Alternatively, interpersonal relationships may provide a buffer against financial hardship. These issues are particularly pertinent to donors who are less financially or socially prepared to handle such strains.

Although an increasing body of literature from small, retrospectively studied, single-center, mostly kidney donor cohorts suggests that living donors can experience significant problems related to interpersonal relationships, work and finances, it remains largely unknown whether liver donors are at similar risk (1). To date, the sparse literature indicates liver donors' relationships with recipients or family members can be strained or can worsen after donation (2–4). Liver donors may experience more family conflicts related to the decision to donate compared with kidney donors (5) and can encounter burdensome donation-related expenses (1,4,6,7).

Studies also suggest how donation-related social and financial outcomes may be mutually affected. Kidney donors can experience financial stresses that could affect their family or spousal relationships because of lost work and wages for both donors and their family caregivers; decreased home productivity; and costs for dependent care, transportation and housing (8–10). A single-center study of liver donors demonstrated the potential financial impact on donors' social relationships due to donors using personal or family savings or retirement funds, asking family or friends for loans, declaring bankruptcy, or having a family member get a second job to pay uncovered donation-related medical expenses (7). Insurability is another financial issue that potentially affects donor relationships. Prior reports demonstrate that some donors have difficulties keeping or obtaining health and life insurance (11–13). On the one hand, studies of liver donors could be expected to reveal more frequent and extensive issues, given the greater magnitude of their donation surgery compared with kidney donation (5). On the other hand, the higher risks associated with liver donation surgery and the potential for complications may lead to more stringent social and financial selection criteria.

These initial studies led to recommendations for further research (7,12–14) to delineate the scope of these issues for liver donors. With this intent, we sought to prospectively survey liver donors enrolled in the nine-center Adult-

to-Adult Living Donor Liver Transplantation Cohort Study 2 (A2ALL-2). The prospective repeated-measures design facilitated the examination of whether social or financial difficulties arose and persisted during the first 2 years after donation. Mutually considering donors' perceptions of poorer social and financial outcomes allowed identification of their coincidence and examination of shared predictors.

## Methods

### **Study design and cohort**

The A2ALL-2 consortium consists of nine North American transplant centers. All centers followed the medical and psychosocial evaluation and exclusion criteria for living liver donor selection now included in current U.S. national policy (15). Centers began prospective study enrollment between February and July 2011 and ended enrollment January 31, 2014. Donors were eligible for the present study if they spoke English and were scheduled for but had not yet undergone liver donation.

### **Procedure**

Potential liver donors were approached by center clinical staff, and informed consent was obtained by center study coordinators before scheduled donation. Survey centers for centralized data collection subsequently contacted donors to complete 30- to 45-min telephone surveys before donation (i.e. within 1 mo) and at 3, 6, 12, and 24 mo after donation. Donors who did not reach an interview time period by the end of study follow-up on July 15, 2014, were administratively censored at that time point (29 censored at 1 year and another 66 censored at 2 years after donation). Participants were offered \$20 for each interview completed. Interviewers used computer-assisted phone interviews for data collection. This approach ensures that interviewers use consistent wording, eliminates independent data entry and minimizes transcription and coding errors. After initial training, interviewers were monitored for quality assurance and underwent periodic retraining.

The study was approved by the institutional review and privacy boards of the University of Michigan Data Coordinating Center and all participating centers.

### **Measures**

**Social relationship outcomes following donation:** We chose key items related to donors' perceptions of interpersonal relationship experiences from donation-specific instruments created and validated previously (16) and used extensively in kidney, liver and bone marrow donation research (17–24) (descriptors and item scales are shown in Table 1).

**Financial outcomes following donation:** Donors' experiences of financial difficulties from health-related expenses and changes in employment and health or life insurance benefits were obtained using the Financial Burden of Donation measure (2,3,25,26) (Table 1).

**Predictors of social relationship and financial outcomes:** Potential predictors included donor demographics, clinical characteristics, donor–recipient relationship and whether the donor was aware of recipient death before each survey (Table 1). We also tested whether early recipient death (within 3 mo after donation) was associated with outcomes.

Additional predictors included predonation survey items assessing donor relationship and financial perceptions, expectations and concerns about

**Table 1:** Instruments used to assess postdonation relationship and financial domains and their predonation predictors

Measure	Instrument and scoring	Scoring of instrument or items	Source
Postdonation donor family relationships outcomes			
Family relationship quality <sup>1</sup>	Single item asked about change compared to before donation, rated on a 5-point scale from "gotten much worse" to "improved greatly"	Improved (scores of $\geq 4$ ) versus not	(16)
Family relationship more difficult <sup>1</sup>	Single item asked about change compared with before donation, rated on 10-point scale from "not at all true" to "very true"	Agree (scores of $\geq 6$ ) versus not	(16)
Family expressed gratitude <sup>1</sup>	Single item asked about gratitude expressed since donation, rated on 10-point scale from "not at all true" to "very true"	Agree (scores of $\geq 6$ ) versus not	(16)
Family holds me in higher esteem <sup>1</sup>	Single item asked about being held in higher esteem by family since donation, rated on 10-point scale from "not at all true" to "very true"	Agree (scores of $\geq 6$ ) versus not	(16)
Postdonation spouse/partner relationships outcome			
Relationship with spouse/partner changed <sup>1</sup>	Single item asked about change compared with before donation, rated on 5-point scale from "gotten much worse" to "improved greatly"	Improved (scores of $\geq 4$ ) versus not	(16)
Postdonation recipient relationships outcomes			
Relationship with recipient <sup>1</sup>	Single item asked about change compared to before donation, rated on 5-point scale from "gotten much worse" to "improved greatly"	Improved (scores of $\geq 4$ ) versus not	(16)
Donor recipient relationship quality <sup>1</sup>	Single item asked about overall quality of the relationship with the recipient since donation, rated 5-point scale from "poor" to "excellent"	Very good to excellent (scores of $\geq 4$ ) versus all other responses	(16)
Feel closer to the recipient <sup>1</sup>	Single item asked about feeling closer to the recipient than before donation, rated on 4-point scale from "strongly disagree" to "strongly agree"	Agree versus not	(16)
Worried about your recipient <sup>1</sup>	Single item asked about degree of worry, rated on 4-point scale	Worried versus not	(16)
Want more contact with recipient	Single item asked about contact preferences, rated as "yes, would like a lot more communication"; "yes, would like a little more communication"; or "no, would not like more communication"	Yes versus no	(16)
Interactions with recipient <sup>1</sup>	Seven items asked about qualities of their interactions with recipient as positive or negative on a 7-point semantic differential scale (e.g. close vs. distant)	Positive interactions (scores of $\geq 5$ ) versus not	(16)
Postdonation financial outcomes			
<i>Cost questions were asked about out of pocket costs not covered by insurance and "Since we last spoke with you..."</i>			
Donation related costs were a burden <sup>1</sup>	Single item about whether costs were significant financial burden, 4-point scale (1 = no; 2 = yes, mild burden; 3 = yes, moderate burden; 4 = yes, severe burden)	Yes versus no	(2)
Nonreimbursed medical costs	Two items asked about whether the donor had had medical bills and medication costs	Yes (if either endorsed) versus no	(2,3)
Nonreimbursed non-medical costs	Five items asked about whether the donor had had lost wages, family/child care, transportation/parking, housing, food	Yes (if any endorsed) versus no	(2,3)
Costs compared to expectations <sup>1</sup>	Single item, rated as "less than expected," "more than expected," or "about as expected"	More than expected versus not	(2)
<i>Job and income questions asked "Since we last spoke with you ... because of your donation"</i>			
Change in income due to donation	Single item	Decreased versus not	(2)
Changed or modified your job due to donation	Single item	Yes versus no	(2)

(Continued)

**Table 1.** *Continued*

Measure	Instrument and scoring	Scoring of instrument or items	Source
<i>Insurance questions were asked "Since we last spoke with you . . . because of the donation"</i>			
Had postdonation problems getting or keeping health insurance	Two items asked whether donor had trouble getting or keeping health insurance	Yes versus no (no includes "tried to get/keep insurance; had no problems" and "did not try to get new insurance")	(26)
Had postdonation problems getting or keeping life insurance	Two items asked whether donor had trouble getting or keeping life insurance	Yes versus no (no includes "tried to get/keep insurance; had no problems" and "did not try to get new insurance")	(26)
Currently have health insurance	Single item asking about whether donor had medical insurance at the time of interview	"Yes, have insurance" versus "no, do not have insurance"	(26)
Predonation predictor variables "Black sheep"	Two items asked about whether family was generally approving and accepting of the donor's life and if the donor had done anything major in his or her life of which family did not approve	Family disapproval present versus not	(16)
Anyone encouraged donor to donate	Nine items asked about whether the recipient, family, and extended family or friends had encouraged donation	Anyone versus no one encouraged donor	(16)
Anyone discouraged donor to donate	Nine items asked about whether the recipient, family, and extended family or friends had discouraged donation	Anyone versus no one discouraged donor	(16)
Ambivalence	Seven items asked about whether the donor had lingering feelings of hesitation and uncertainty about whether to donate, rated on 8-point scale, higher scores reflect greater ambivalence	Continuous summary score from 0 (no ambivalence) to 7 (highest ambivalence)	(16)
Positive relationship with recipient	Three items asked about quality of relationship with the recipient, rated on 7-point scale from "not at all accurate" to "very accurate" about whether the donor felt the recipient saw eye to eye on most issues, had a warm and close relationship, and generally enjoyed each other's company (excluded those with no relationship with recipient)	Average of items	(16)
Spouse/partner or parents disagree with donation decision	Two items asked about whether the donor's spouse/partner or parents supported or disagreed with the donation decision	Yes, disagreed versus not	(16)
Patient Health Questionnaire 9, depression	Nine items asked about severity of symptoms of depression, each rated on a scale from 0 to 3	Continuous summary score from 0 (no depressive symptoms) to 27 (maximal depressive symptoms)	(35)
Occupation classification	One item asked about predonation occupation	Classified as semiprofessional/professional versus technical/clerical or lower-level position based on the Hollingshead Index of Social Position	(36)
Days donor anticipated being in hospital	One item asked about how many days the donor expected to be in the hospital following donation	Number of days	(16)
How long donor thinks he or she will be off work	One item asked about how many months the donor expected to be off work, if employed	<1, 1–3 and >3 mo and not employed	(16)
How long donor thinks it will take until he or she feels back to normal	One item asked about how long the donor expected it would take to feel back to normal	<1, 1–3 and >3 mo	(16)
Concerns about missing work	One item asked whether donor had concerns about missing time from work	Yes versus no	(16)
Concerns about who would pay for procedure	One item asked whether donor had concerns about who would pay	Yes versus no	(16)

<sup>1</sup>These outcomes were dichotomized in the analyses because of their highly skewed distributions and because we were interested in identifying subgroups of patients with bad (or good) social and financial outcomes and predictors of those subgroups.

postdonation experiences (16); the Patient Health Questionnaire 9 depression score (Table 1); and predonation household income, employment status and occupation.

### Statistical analysis

Demographics of survey respondents and nonrespondents were compared using t-tests for continuous variables and chi-square or Fisher exact tests for categorical variables. Among respondents, we similarly compared completers, those who withdrew consent during the study period (permanent refusers or study dropouts), intermittent refusers (refused one or more interviews but were willing to be called again) and administratively censored donors.

Descriptive statistics were used to examine social and financial outcomes at each time point. Correlation coefficients were calculated for each pair of outcomes at 3 mo and 2 years after donation to assess relationships among outcomes shortly after donation and at longest follow-up, respectively.

Outcomes with 10–90% prevalence at any time point were chosen for modeling to avoid limited generalizability with sparse outcomes. To investigate changes in social and financial outcomes and to identify predonation predictors, repeated-measures logistic regression models were fit among donors who completed the predonation survey and at least one postdonation survey. Generalized estimating equation models with sandwich standard error estimators were used. We started with an unstructured covariance structure and then simplified to an exchangeable correlation structure if variances and covariances were homogenous. The postdonation time point was retained in the models whether or not it was statistically significant and was used as a categorical variable because many outcomes did not change linearly over time. Overall tests across all time points and pairwise tests were conducted to test for significant differences in outcomes over time.

Variable selection was guided by the method of best subsets (27). Final models included predictors that were statistically significant at the level of  $p = 0.05$ . Categorical variables were included if overall tests were statistically significant or if any pairwise test was statistically significant after using the Bonferroni correction for multiple comparisons (28).

We also examined whether outcomes differed across centers by conducting overall significance tests for center in the final models. To assess whether adjusting for centers affected the effect sizes of other predictors, we compared the model results before and after controlling for centers in sensitivity analyses. In financial outcome models, we compared the Canadian center with all U.S. sites combined because of differences in health insurance.

Because 12 donors (5%) included in the models were missing predonation income, we also conducted two sets of sensitivity analyses by replacing all missing incomes with either the lowest or highest income category.

A prior A2ALL report showed that the majority of donor complications occur in the first weeks following donation (29). To test whether donor complications that occurred beyond 1 mo influenced responses at later time points, we performed sensitivity analyses using complications or rehospitalization within 3 mo after donation among those who had clinical data available at 3 mo.

All analyses were performed using SAS version 9.4 (SAS Institute, Inc., Cary, NC).

## Results

Overall, 91.2% (271 of 297) of eligible donors gave consent and were interviewed at least once during the study, with 245 interviewed both before and after donation, 8 before donation only and 18 after donation only (Figure 1).

Demographics and clinical characteristics of respondents are presented in Table 2. We compared available demographics between nonrespondents ( $n = 26$ ) and respondents ( $n = 271$ ), and no significant differences were found ( $p = 0.74$  for gender,  $p = 0.36$  for age and  $p = 0.11$  for race/ethnicity). Nonrespondents were 54% female, 69% non-Hispanic white, 15% Hispanic and 16% other race/ethnicity and had a mean age of 34.70 years (standard deviation 9.28 years). Among respondents, there were few differences in demographics and clinical characteristics of completers, permanent refusers, intermittent refusers and administratively censored donors (all  $p$ -values  $\geq 0.12$ ).

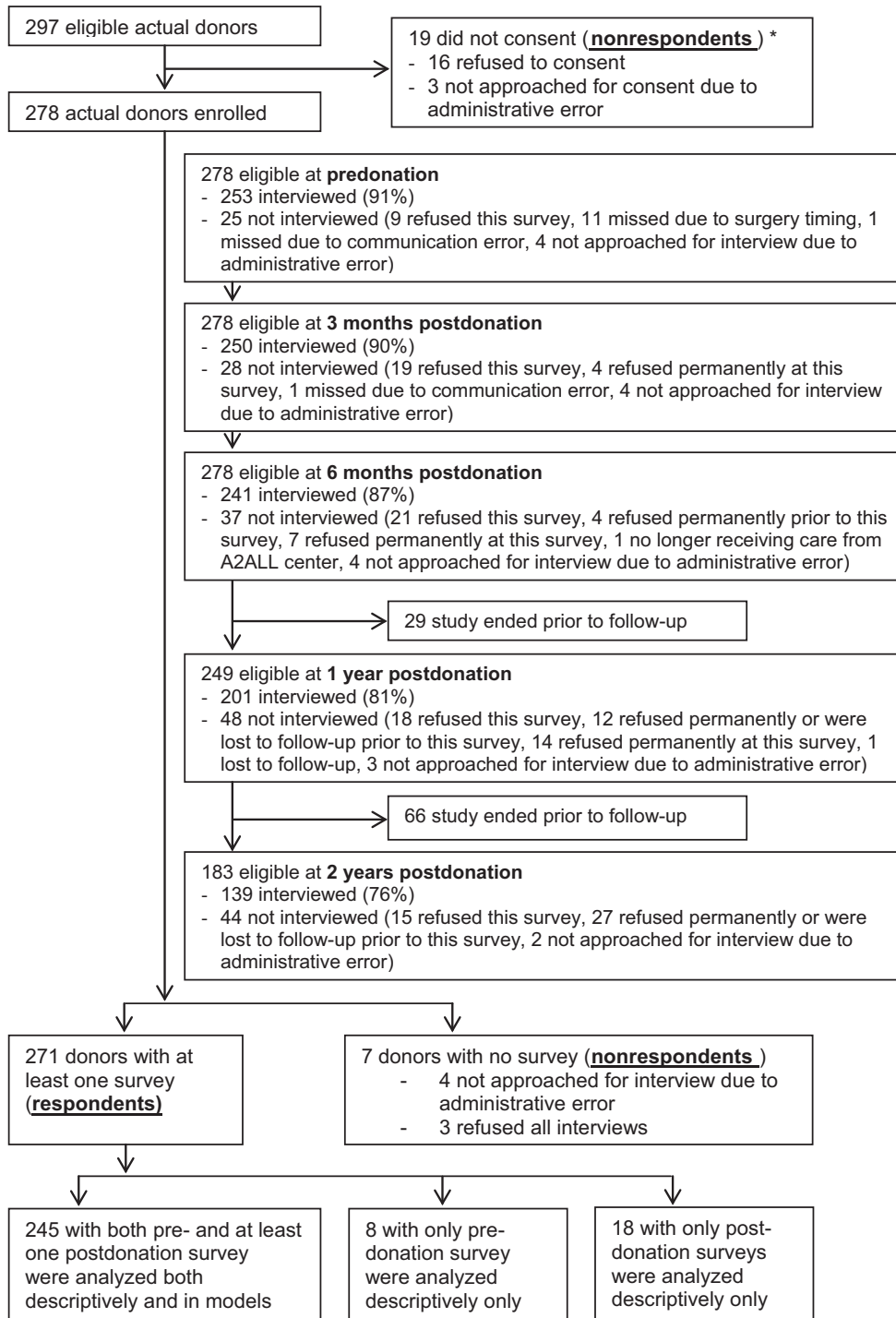
### Prevalence of postdonation social relationship outcomes

At each postdonation time point, 25–34% of donors indicated that their family and spouse or partner (if applicable) relationships improved (Table 3), whereas the majority (>60%) reported that relationships stayed the same as before donation. Among donors who had interactions with their recipients before the postdonation interview ( $n = 239$ ), a greater proportion ( $\geq 54\%$  at every time point) reported improved recipient relationships. Less than 3% reported that their relationships with their recipients got worse at any time point. The vast majority of donors reported higher quality recipient relationships after donation (86–93% across time points) and feeling closer to their recipients (77–84%). More than 90% reported that their interactions with recipients were rewarding, comfortable, easy, positive, relaxed, close, and natural (Table S1).

Nearly 42% of donors reported that they worried about their recipients at 3 mo after donation, but this proportion was 25–29% by 1–2 years after donation (Table 3). Similarly, the percentages of donors reporting that their families expressed gratitude and held them in higher esteem were both highest at 3 mo (82% and 54%, respectively) and were 10% lower at 2 years after donation.

### Prevalence of postdonation financial outcomes

Endorsement of donation-related adverse financial outcomes was highest at 3 mo after donation and lowest at 1 or 2 years after donation (Table 4). Although health insurance was not required by half of the U.S. centers or by the Canadian center, >92% of donors reported having health insurance after donation. Nevertheless, in total, 37% incurred out-of-pocket donation-related medical



Note: There were 30 potential donors consented to the study but did not donate. These 30 subjects were not included in this flow chart.

<sup>†</sup> The last subject was enrolled January 17, 2014 and the last surgery was performed January 28, 2014 for the same subject.

\* The donation statuses for these 19 donor candidates were unknown as they didn't consent to this study.

**Figure 1: Participant flow diagram.** This diagram shows the number of eligible actual donors who consented to the study, who were interviewed by the survey center and who were included in descriptive analyses and models. Donors were eligible at each time point if they had reached that time point before being administratively censored at the end of study on July 15, 2014.<sup>†</sup>

**Table 2:** Demographic and donation-related characteristics of respondents (n = 271)

Characteristic	% (n) or Mean (SD)
Female	57.2% (155)
Age at donation (years)	36.79 (10.51)
Race/ethnicity	
Non-Hispanic white	80.4% (218)
Hispanic	9.2% (25)
Native American or Alaskan Native	1.8% (5)
Asian	3.0% (8)
Black or African American	2.6% (7)
Native Hawaiian or other Pacific Islander	2.6% (7)
Other	0.4% (1)
Education at survey	
High school or less	17.3% (47)
Vocational or some college	29.2% (79)
College graduate	28.8% (78)
Postgraduate	18.1% (49)
Unknown	6.6% (18)
Married or long-term partner	63.1% (171)
Relation to transplant recipient	
First-degree relative	53.1% (144)
Parent	2.2% (6)
Child	36.2% (98)
Sibling	14.8% (40)
Spouse/partner	6.3% (17)
Other biological or nonbiological relative	19.2% (52)
Unrelated <sup>5</sup>	21.4% (58)
BMI at donation (kg/m <sup>2</sup> )	
<18.5	1.1% (3)
18.5–24.9	35.4% (96)
25.0–29.9	46.5% (126)
≥30	17.0% (46)
Postdonation length of hospital stay (days)	5.50 (1.99)
Range	1–24
Donating right lobe versus left lobe or left lateral segment	84.1% (228)
Number of postoperative complications during the first month after donation <sup>1</sup>	
0	80.4% (218)
≥1	19.2% (52)
Number of rehospitalizations during the first month after donation <sup>1</sup>	
0	91.5% (248)
≥1	7.7% (21)
Postdonation recipient vital status from donor-reported survey data (n = 263)	
Donor ever aware of recipient death <sup>3</sup>	10.3% (27)
How long after donation surgery did the recipient die	
0–2.9 mo	5.7% (15)
3–5.9 mo	2.3% (6)
6–11.9 mo	1.5% (4)
12–24 mo	0.8% (2)
Weeks after donation that recipient death occurred (n = 27)	16.11 (18.22)
Predonation predictors from survey data (n = 253)	
“Black sheep” donor	28.5% (72)
Anyone encouraged donor to donate <sup>4</sup>	13.4% (34)
Anyone discouraged donor to donate <sup>4</sup>	46.6% (118)

(Continued)

**Table 2.** Continued

Characteristic	% (n) or Mean (SD)
Ambivalence scale (0 = no ambivalence; 7 = highest ambivalence)	1.97 (1.58)
Positive relationship with recipient (1 = not at all accurate; 7 = very accurate) (n = 240)	6.03 (0.97)
Spouse/partner or parents disagree with donor’s decision to donate	7.5% (19)
PHQ-9 depression score (0 = no depressive symptoms; 27 = maximal symptoms)	1.45 (2.30)
Range	0–16
Employed <sup>1</sup>	
Full time	65.1% (164)
Part time	15.9% (40)
Unemployed or retired	19.0% (48)
Household income <sup>2</sup>	
≤\$40 000	22.8% (55)
\$40 001–80 000	27.4% (66)
\$80 001–120 000	26.1% (63)
>\$120 000	23.7% (57)
Household size, mean (SD)	3.28 (1.54)
Median (IQR)	3 (2–4)
Hollingshead categories	
Semiprofessional/professional	56.1% (142)
Technical/clerical or lower-level position	43.9% (111)
Days donor expects to be in hospital after donation	5.77 (1.43)
How long donor expects to be off work <sup>1</sup>	
<1 mo	26.1% (66)
1–3 mo	35.6% (90)
>3 mo	21.0% (53)
Not employed	16.6% (42)
How long donor thinks it will be until he or she feels back to normal <sup>1</sup>	
<1 mo	9.5% (24)
1–3 mo	77.9% (197)
>3 mo	11.9% (30)
Concerns about missing work	39.5% (100)
Concerns about who would pay donation costs	13.0% (33)

Variables had no missing data except as noted. IQR, interquartile range; PHQ-9, Patient Health Questionnaire 9; SD, standard deviation.

<sup>1</sup>Missing < 1%.

<sup>2</sup>Missing = 5% (n = 12).

<sup>3</sup>Five donors reported that they did not know recipient vital status during at least one time point.

<sup>4</sup>Among 34 donors who were encouraged to donate, 27 (79%) were encouraged by first-degree relatives, 16 (47%) by spouses or partners, 14 (41%) by other relatives, and 22 (65%) by unrelated people. Among 118 donors who were discouraged, 55 (47%) were discouraged by first-degree relatives, 21 (18%) by spouses or partners, 27 (23%) by other relatives, and 70 (59%) by unrelated people. In addition, 22 (65% of 34) were encouraged and 38 (32% of 118) were discouraged by more than one type of relationship.

<sup>5</sup>Nine donors were anonymous in this unrelated donor–recipient relationship group.

**Table 3:** Social relationship outcomes over time

Outcome	3 mo after donation (n = 250)	6 mo after donation (n = 241)	1 year after donation (n = 201)	2 years after donation (n = 139)
All donors (n = 263; 100%)				
Family relationship quality <sup>1</sup>				
Improved	33.2% (83)	31.3% (75)	29.9% (60)	25.9% (36)
Stayed the same	63.2% (158)	66.3% (159)	64.2% (129)	71.9% (100)
Got worse	3.6% (9)	2.5% (6)	6.0% (12)	2.2% (3)
Family expressed gratitude, % agree <sup>2</sup>	82.4% (206)	82.0% (196)	77.1% (155)	74.6% (103)
Family holds me in higher esteem, % agree <sup>3</sup>	54.4% (136)	53.3% (128)	48.8% (98)	44.9% (62)
Family relationship more difficult, % agree <sup>4</sup>	7.2% (18)	4.6% (11)	7.0% (14)	7.2% (10)
Donors who are married or live with a long-term partner and spouse/partner is not the recipient (n = 162; 61.6%)	n = 148	n = 132	n = 106	n = 74
Relationship with spouse/partner, quality <sup>1</sup>				
Improved	33.8% (50)	29.0% (38)	29.2% (31)	33.8% (25)
Stayed the same	61.5% (91)	62.6% (82)	65.1% (69)	62.2% (46)
Got worse	4.7% (7)	8.4% (11)	5.7% (6)	4.1% (3)
Donors whose recipients are alive and donor had interactions with their recipients (n = 239; 90.9%) <sup>1,5</sup>	n = 229	n = 213	n = 181	n = 120
Relationship with recipient, quality				
Improved	53.7% (123)	56.8% (121)	54.1% (98)	55.8% (67)
Stayed the same	43.7% (100)	40.4% (86)	43.1% (78)	42.5% (51)
Got worse	2.6% (6)	2.8% (6)	2.8% (5)	1.7% (2)
Donor recipient relationship quality, % very good to excellent	92.6% (212)	88.3% (188)	86.2% (156)	88.3% (106)
Closer to recipient, % agree	84.3% (193)	78.9% (168)	77.3% (140)	84.2% (101)
Donors whose recipients are alive (n = 247; 93.9%)	n = 234	n = 220	n = 184	n = 122
Worried about recipient, % worried	41.9% (98)	35.5% (78)	25.0% (46)	28.7% (35)
Want more contact, % yes <sup>4</sup>	33.8% (79)	32.4% (71)	31.1% (57)	32.8% (40)

Data are shown as % (n) or mean (standard deviation). Sensitivity analyses among only donors who completed all surveys (n = 119) showed results similar to those who completed at least one postdonation survey (n = 263).

<sup>1</sup>n = 1 missing at 6 mo.

<sup>2</sup>n = 2 missing at 6 mo and n = 1 missing at 2 years.

<sup>3</sup>n = 1 missing at 6 mo and n = 1 missing at 2 years.

<sup>4</sup>n = 1 missing at 6 mo and n = 1 missing at 1 year.

<sup>5</sup>Donors whose recipients died or who were not aware of recipient vital status or donors who had no interactions with their recipients responded "not applicable" to these recipient relationship questions.

expenses not covered by insurance including medical bills and medication costs. Some donors continued to experience medical expenses as long as 1 and 2 years after donation (12.4% and 9.4%, respectively). Cumulatively, 75% of donors reported some nonmedical out-of-pocket expenses (i.e. 45% lost wages, 60% transportation, 27% housing, 41% food expenses, and 7% child or family care costs) (Table S2). The proportions of donors who reported that donation-related costs were a burden were 40% at 3 mo and 19% at 2 years after donation; cumulatively, 44% reported this burden. Almost 12–16% of donors, 24% cumulatively, reported that donation costs were more than expected, and percentages were similar over the follow-up period.

Among donors employed at least part time before donation (n = 196), 34% reported changing jobs or modifying work because of donation at 3 mo after donation, but only 1% reported doing so at 2 years; cumulatively, 40% reported such a change. Although cumulatively 7% changed to jobs with less manual labor, the majority of donors who noted other changes—30% total across all

time points—reported changes due to reduced working hours. The proportions reporting decreased income due to donation were 41% at 3 mo and 1% at 2 years.

Difficulties getting or keeping health or life insurance ranged from 1% to 4% across all time points. Cumulatively, 5% reported difficulties with health insurance and 3% with life insurance. Across the time points, 2–7% (12% cumulatively) reported no current health insurance. Although Canadian donors have access to governmental health insurance, which covers medical services, they may also have additional insurance through an employer or purchase private insurance to pay for costs not covered by their universal health care, such as prescription medications (separate U.S. and Canadian data are shown in Table S3).

### **Correlations between social and financial outcomes**

The financial outcomes were significantly correlated with each other at 3 mo after donation ( $r_p$  between 0.23 and 0.41) (Table 5) but had little intercorrelation at 2 years. Several social relationship outcomes were significantly



**Table 4:** Financial outcome characteristics over time

Outcome	3 mo after donation (n = 250)	6 mo after donation (n = 241)	1 year after donation (n = 201)	2 years after donation (n = 139)
Donation costs were a burden <sup>1</sup>	39.6% (99)	28.4% (67)	25.4% (51)	19.4% (27)
Incurred medical costs related to donation <sup>1,2</sup>	26.4% (66)	16.5% (39)	12.4% (25)	9.4% (13)
Incurred nonmedical costs related to donation <sup>1</sup>	73.2% (183)	36.9% (87)	20.4% (41)	13.7% (19)
Costs compared with expectations <sup>3</sup>				
Less than expected	8.1% (20)	13.2% (31)	11.0% (22)	14.4% (20)
About what was expected	75.7% (187)	71.8% (168)	77.5% (155)	73.4% (102)
More than expected	16.2% (40)	15.0% (35)	11.5% (23)	12.2% (17)
Changed jobs or modified work due to donation <sup>4,5</sup>	34.2% (63)	12.6% (22)	2.1% (3)	1.0% (1)
Personal income affected by donation <sup>5,6</sup>				
Decreased	41.1% (76)	8.4% (15)	4.1% (6)	1.0% (1)
No change	58.4% (108)	87.7% (157)	92.5% (135)	98.1% (101)
Increased	0.5% (1)	3.9% (7)	3.4% (5)	1.0% (1)
Problems getting or keeping health insurance <sup>7,8</sup>	2.4% (6)	2.1% (5)	1.0% (2)	3.6% (5)
Problems getting or keeping life insurance <sup>7,8</sup>	1.2% (3)	0.8% (2)	1.0% (2)	1.4% (2)
Currently have no health insurance <sup>6</sup>	7.2% (18)	6.3% (15)	6.5% (13)	2.2% (3)

Data are shown as % (n). Sensitivity analyses among only donors who completed all surveys (n = 119) showed results similar to those who completed at least one postdonation survey (n = 263).

<sup>1</sup>n = 5 missing at 6 months.

<sup>2</sup>In the United States, the donation surgery is paid for primarily by the recipient’s insurance, although the donor’s insurance may be charged for some portion. In Canada, the governmental insurance pays for the donation surgery.

<sup>3</sup>n = 3 missing at 3 mo, n = 7 missing at 6 mo, and n = 1 missing at 1 year.

<sup>4</sup>n = 1 missing at 3 mo, n = 8 missing at 6 mo, and n = 4 missing at 1 year.

<sup>5</sup>Applicable to 196 donors who were employed at least part time before donation (n = 185 at 3 mo, n = 182 at 6 mo, n = 146 at 1 year, and n = 103 at 2 years after donation).

<sup>6</sup>n = 3 missing at 6 mo.

<sup>7</sup>Although all Canadian donors are provided with health insurance, Canadian donors were also included in these percentages along with all other (U.S.) donors in the cohort. Donors who did not have health or life insurance and did not try to get new health or life insurance were counted as having no problems (17, 14, 12, and 2 donors for health insurance and 71, 68, 62, and 41 donors for life insurance at 3 mo, 6 mo, 1 year, and 2 years after donation).

<sup>8</sup>n = 4 missing at 6 mo.

correlated with each other at both 3 mo and 2 years after donation. Improved relationships were intercorrelated among all relationship outcomes for family, spousal or partner, and recipient relationships ( $r_{\phi}$  between 0.21 and 0.56). Donors who reported improved family, spousal or recipient relationships were also more likely to report that their families held them in higher esteem ( $r_{\phi}$  between 0.16 and 0.39). Those whose families expressed gratitude were also more likely to report that their families held them in higher esteem ( $r_{\phi} = 0.38$  at 3 mo and  $r_{\phi} = 0.49$  at 2 years). Nevertheless, there was little correlation between financial and relationship outcomes at 3 mo or 2 years.

**Predictors of social relationship outcomes**

Table 6 shows results from repeated-measures regression models for social relationship outcomes. The only outcome that showed significant differences across time was whether donors were worried about recipients (overall  $p < 0.001$ ), which was double the odds at 3 mo compared with 2 years ( $p = 0.002$ ).

We modeled improved donor family, spousal and recipient relationships (vs. no improvement) because the

percentages of donors expressing poorer relationships were too small for modeling. Donors who were encouraged by someone to donate were more likely to report improved family relationships, and older donor age was associated with an improved recipient relationship. There were no significant predictors of improved spousal relationship. For each outcome, when donors whose relationship worsened were excluded, the results were unchanged; therefore, these results are driven mainly by the comparison of donors whose relationships improved and those whose relationships stayed the same.

Donors donating to first-degree relatives or to their spouses or partners were more worried about their recipients compared with those donating to unrelated recipients (Table 6). Female gender, BMI  $\leq 30$ , predonation ambivalence about donation and positive recipient relationship were also associated with higher odds of being worried. Donors donating to first-degree or other relatives were more likely to report being held in higher esteem and having gratitude expressed by their families, whereas donors whose recipients died were less likely to report such outcomes. An additional predictor of

**Table 5:** Correlations between selected social relationship and financial outcomes at 3 mo (light grey) and 2 years (dark grey) after donation

	Financial				Social				
	Costs were a burden	Decreased income due to donation	Changed/modified jobs due to donation	Family relationship improved	Spousal relationship improved	Recipient relationship improved	Worried about recipient	Family holds me in higher esteem	Family expressed gratitude
Financial	1	<b>0.417</b>	<b>0.234</b>	0.089	0.081	0.037	-0.056	0.052	0.052
Costs were a burden		1	<b>0.310</b>	0.092	0.070	0.050	-0.021	0.029	-0.096
Decreased income due to donation			1	0.027	-0.060	-0.030	-0.016	0.079	0.019
Changed/modified jobs due to donation				1	<b>0.428</b>	<b>0.420</b>	-0.020	<b>0.390</b>	0.192
Social					1	<b>0.216</b>	-0.012	<b>0.247</b>	0.115
Family relationship improved	0.125	-0.059	-0.059	1	<b>0.421</b>	1	0.016	<b>0.162</b>	0.043
Spousal relationship improved	0.180	N/A	N/A	<b>0.561</b>	1	<b>0.216</b>	-0.012	<b>0.247</b>	0.115
Recipient relationship improved	0.049	-0.113	-0.113	<b>0.422</b>	<b>0.421</b>	1	0.016	<b>0.162</b>	0.043
Worried about recipient	<b>0.233</b>	0.167	-0.066	0.022	-0.030	-0.057	1	-0.050	0.012
Family holds me in higher esteem	0.161	-0.087	-0.087	<b>0.359</b>	<b>0.347</b>	<b>0.304</b>	0.111	1	<b>0.378</b>
Family expressed gratitude	0.025	-0.175	-0.175	0.233	0.078	<b>0.227</b>	0.098	<b>0.493</b>	1

Correlation coefficients that were significantly different ( $p < 0.05$ ) from 0 are shown in bold type. Because some outcomes apply only to subgroups of the cohort and because of participant dropout, each correlation was calculated based on different numbers of observations, which ranged from 118 to 250 at 3 mo and from 64 to 139 at 2 years after donation. Two correlation coefficients are missing because no donors with a spouse and a job before donation ( $n = 57$ ) indicated at 2 years that they decreased income or changed/modified jobs due to donation.

**Table 6:** Predictors of social relationship outcomes from repeated-measures logistic regression models

Predictors <sup>1</sup>	Family relationship improved (n = 245)		Spouse relationship improved <sup>d</sup> (n = 141)		Recipient relationship improved <sup>e</sup> (n = 224)		Worried about recipient <sup>4</sup> (n = 231)		Family holds me in higher esteem (n = 245)		Family expressed gratitude (n = 245)		
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	
Postdonation time point <sup>5</sup>		0.17		0.20		0.82		<0.001		0.12		0.14	
3 mo versus 2 years	1.41 (0.98–2.02)	0.06	1.40 (0.90–2.16)	0.12	1.03 (0.73–1.46)	0.86	2.01 (1.27–3.19)	0.002	1.49 (1.04–2.15)	0.03	1.65 (1.06–2.57)	0.03	
6 mo versus 2 years	1.32 (0.94–1.87)	0.11	1.18 (0.73–1.89)	0.47	1.14 (0.82–1.57)	0.44	1.43 (0.89–2.28)	0.13	1.43 (1.04–1.98)	0.03	1.50 (0.98–2.29)	0.08	
1 versus 2 years	1.08 (0.76–1.53)	0.67	0.89 (0.59–1.34)	0.55	1.10 (0.83–1.47)	0.50	0.79 (0.48–1.29)	0.35	1.16 (0.85–1.59)	0.35	1.13 (0.75–1.72)	0.56	
Predonation psychosocial predictors													
Anyone encouraged donor to donate	2.25 (1.24–4.07)	0.02									2.77 (1.19–6.45)	0.008	
Ambivalence to donate (1-unit increase on scale of 0 [no ambivalence] to 7 [highest ambivalence])									1.27 (1.09–1.49)	0.003			
Positive relationship with recipient								1.37 (1.00–1.88)	0.049				
Demographic/clinical predictors													
Donor recipient relationship										0.003		<0.001	
First-degree relative versus unrelated								2.62 (1.28–5.33)	0.007	2.09 (1.25–3.50)	0.005	5.74 (3.12–10.57)	<0.001
Spouse/partner versus unrelated								7.15 (2.66–19.22)	0.001	1.45 (0.51–4.15)	0.48	3.35 (1.10–10.22)	0.03
Other biological or nonbiological relative versus unrelated								1.73 (0.73–4.06)	0.22	2.43 (1.29–4.56)	0.006	7.90 (3.32–18.78)	<0.001
Recipient death (time dependent)													
Female versus male										0.45 (0.21–0.92)	0.03	0.32 (0.14–0.76)	0.04
Age at donation (per 10-year increase)										1.99 (1.23–3.22)	0.005		
BMI obese versus not obese										0.40 (0.21–0.76)	0.003		

CI, confidence interval; NA, not applicable; OR, odds ratio.

<sup>1</sup>Variables tested but not significant: education, race/ethnicity, marital status, hospitalized within first month after donation, donation complications within first month, length of hospital stay, anyone discouraged to donate, parents or spouse/partner disagreement with donation decision, Patient Health Questionnaire 9 depression score, “black sheep” donor, days donor thinks he or she will be in the hospital, how long donor thinks he or she will be off work or will take until he or she feels back to normal, concerns about missing work and paying for the procedure, employment status, household income, Hollingshead occupation classification.

<sup>2</sup>“Spouse relationship improved” was modeled among donors who were married or had a long-time partner before donation.

<sup>3</sup>“Recipient relationship improved” was modeled among donors who had interactions with the recipient and whose recipients had not died at the interview time point.

<sup>4</sup>“Worried about recipient” was modeled among donors whose recipients had not died at the interview time point.

<sup>5</sup>For the pairwise tests, 2 years after donation was chosen as the reference group because we expected donor outcomes at this time point to be closest to predonation levels.

**Table 7:** Predictors of financial outcomes from repeated-measures logistic regression models

Predictors <sup>1</sup>	Costs were a burden (n = 245)		Decreased income due to donation <sup>2</sup> (n = 196)		Changed or modified jobs due to donation <sup>2,3</sup> (n = 196)	
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
Postdonation time point <sup>4</sup>		<0.001		<0.001		<0.001
3 mo versus 2 years	2.96 (1.96–4.47)	<0.001	86.23 (12.82–580.17)	<0.001	57.94 (6.83–491.42)	<0.001
6 mo versus 2 years	1.75 (1.12–2.72)	0.01	7.87 (1.05–58.96)	0.01	16.07 (1.87–138.29)	<0.001
1 versus 2 years	1.33 (0.87–2.04)	0.18	3.23 (0.38–27.14)	0.21	2.30 (0.22–24.36)	0.43
Length of hospital stay (per day)	1.22 (1.02–1.45)	0.02	1.54 (1.24–1.91)	<0.001		
Predonation predictors						
Time you think you will be off work		0.02		0.02		0.004
1–3 versus <1 mo (and not employed <sup>2</sup> )	1.24 (0.69–2.22)	0.46	1.13 (0.50–2.56)	0.76	0.56 (0.30–1.07)	0.09
>3 versus <1 mo (and not employed <sup>2</sup> )	2.77 (1.45–5.31)	0.004	2.85 (1.24–6.56)	0.02	1.76 (0.88–3.49)	0.13
Concern about who will pay donation costs	3.00 (1.53–5.86)	0.007				
Concern about missing work			3.05 (1.62–5.73)	<0.001		
Household income (per \$10 000 increase)	0.93 (0.87–0.98)	0.009				
Hollingshead scale semiprofessional/professional versus technical/clerical or lower-level position			0.53 (0.29–0.97)	0.046	0.51 (0.29–0.88)	0.02
Ambivalence to donate (1-unit increase on scale of 0 [no ambivalence] to 7 [highest ambivalence])			0.75 (0.62–0.91)	0.008		

CI, confidence interval; OR, odds ratio.

<sup>1</sup>Variables tested but not significant: donor age at donation, sex, race/ethnicity, marital status, education, BMI (obese vs. not obese), hospitalized within first month after donation, donation complications within first month, donor recipient relationship, donor employment status, recipient death (time dependent), how long donor thinks he or she will be in hospital (days), how long donor thinks it will take until he or she feels back to normal, “black sheep” donor, anyone discouraged or encouraged donor to donate, positive relationship with recipient, spouse/partner or parent disagreement with donation decision, and Patient Health Questionnaire 9 depression score.

<sup>2</sup>Donors who were not employed before donation were excluded from modeling of decreased income and changed/modified jobs due to donation.

<sup>3</sup>Household income was also found to be significant for predicting jobs changes or modifications (OR 0.94 for every \$10 000 increase in income; 95% CI 0.88–1.00); however, it was collinear with Hollingshead categories and thus was not included in Table 7.

<sup>4</sup>For the pairwise tests, 2 years after donation was chosen as the reference group because we expected donor outcomes at this time point to be closest to the predonation levels.

family-expressed gratitude was whether anyone had encouraged them to donate.

Early versus late recipient death and predonation financial predictors were not significant in any models.

### **Predictors of poor financial outcomes**

Model results for postdonation financial outcomes are presented in Table 7. Each financial outcome was significantly different across time (overall  $p < 0.001$  for each outcome). The odds of costs being a burden at 3 mo were almost three times the odds at 2 years ( $p < 0.001$ ), and the odds at 6 mo were 1.75 times the odds at 2 years ( $p = 0.01$ ). Similarly, the odds of decreased income or of job changes or modifications due to donation were large and statistically significantly different at 3 and 6 mo compared with 2 years (Table 4).

Donors with longer hospital stay and those who, before donation, anticipated being off work for >3 mo were more likely to report that postdonation costs were burdensome and that their incomes decreased due to donation. Expected time off work was also associated with donors reporting that they changed or modified jobs due to donation; however, donors expecting time off work for 1–3 mo, compared with <1 or >3 mo, were the least likely to change or modify jobs.

Additional predictors associated with higher odds of adverse financial outcomes were predonation concerns about who would pay donation costs; concern about missing work, having lower household income, or having a technical or clerical or lower-level position compared with a semiprofessional or professional position; and a lower level of ambivalence about donating.

Model results that assessed complications and rehospitalizations within 3 mo after donation rather than at 1 mo remained largely the same for all study outcomes, with the same direction and similar effects sizes. The sensitivity analyses evaluating the impact of missing incomes ( $n = 12$ , 5%) showed that all results were unchanged when all missing incomes were replaced with either the lowest or highest income category.

Results were also unchanged when controlling for transplant centers, and the center effect was not significant in any social or financial model. The Canadian center was not significant in any financial models, and other covariate effects were similar.

## Discussion

Our large multisite study of 271 prospectively surveyed living liver donors establishes the scope and persistence of relationship changes and financial issues following donation. Notably, in contrast to some single-center studies of kidney and liver donors that identified worsening of family, spouse or recipient relationships for up to 10–20% (4,14,30), only a small minority (2–8%) of our donors reported such worsening relationships at any time point. More important, in comparison to family or spouse relationships that stayed the same for the majority of donors, more than half reported improved recipient relationships, and these changes did not diminish over the 2-year follow-up period. This is similar to a cross-sectional single-center report with 51% of donors reporting improved recipient relationships following donation (2). Even larger percentages (77–93%) reported closer and higher quality relationships with their recipients. Older donors were more likely to experience positive relationship changes with their recipients, perhaps reflecting greater maturity or longer term relationships.

Positive relationship experiences, such as being held in higher esteem or feeling gratitude from the family, were not sustained over time and decreased by 6 mo after donation, suggesting that donors may experience less positive affirmation over time. More worrisome were the findings that donors whose recipients died were less likely to report experiencing being held in higher esteem or gratitude from their families; perhaps as the families grieved, the generosity and sacrifice of the donor lost prominence or families were less capable of expressing such feelings in their grief. Although transplant programs are typically attentive to the emotional well-being of donors who have lost their recipients, paying additional attention to the family dynamics may guide the care of donors at this vulnerable time. Although a donor's own recovery is typically the focus of their postdonation clinical visits, inquiring about how their recipient is recovering may identify specific concerns, particularly for female

and ambivalent donors, that can be addressed in postdonation counseling.

Whereas donors perceived positive experiences in their relationships related to donation, nearly half reported experiencing negative financial outcomes (e.g. burdensome costs, medical expenses, lost wages). Although we believed poorer relationship and financial outcomes might coincide, few reported worsening relationships. We also did not find the converse, that perceived relationship improvements were associated with less financial stress. Although removing financial disincentives is widely supported, donation should be at least “cost neutral” (31) so that the most financially vulnerable are not exploited or excluded from donation. Rather than being cost neutral, we found that the majority of donors reported some out-of-pocket expenses. For 44% of donors, these costs were a significant financial burden during at least one assessment point despite the relatively high average household income of our donors. Not surprisingly, those with lower household income were at higher risk for poorer financial outcomes. Many donors were concerned, even before donating, about missing work (40%) and about who would pay for the procedure (13%), and 21% anticipated being off work for >3 mo. These donors were subsequently more likely to experience poorer financial outcomes, suggesting that they accurately anticipated postdonation financial stresses before donation. Conversely, donors who expected to be off work <1 mo were also more likely to experience financial issues, perhaps related to the unrealistic expectations of their return-to-work time frame. The association of length of hospital stay with burdensome costs and decreased income further demonstrates the uncertainty of predicting future costs related to donation. Donors in nonprofessional positions were also more likely to change or modify jobs, perhaps representing the greater physical demands of those positions. Consequently, those who were most financially vulnerable were most likely to experience poor financial outcomes.

In an earlier survey, a substantial number of transplant centers reported having donors decline donation because of concerns about lack of health insurance (13). Although most of our donors were insured, 37% reported donation-related medical expenses that were not covered by insurance. In January 2014, the Patient Protection and Affordable Care Act mandated health care coverage for all U.S. residents and made discrimination in the provision of health insurance based on preexisting conditions illegal (32), potentially eliminating some insurance barriers. Nevertheless, complete coverage for all donation services (e.g. no copays or deductibles) still must be addressed. That  $\approx 10\%$  of our donors were still incurring medical expenses at 1 and 2 years after donation highlights that time-limited recipient insurance coverage after donation is inadequate. A prior study of Canadian donors

found that 39% had medical expenses that were not covered by their governmental insurance (2). In addition, an earlier study using hypothetical liver donor cases found on telephone inquiries that life insurance companies were 50% less likely to offer premium rates to donors compared with other persons or were unwilling to underwrite donors (11).

We recognize several study limitations. A longer follow-up period might have identified higher rates of health and life insurance problems, as were discovered in a study of kidney donors with mean follow-up of 8–9 years (32). In our sample, financial outcomes were self-reported and were not verified with actual costs, out-of-pocket expenses, income changes or job modifications. We did not ask specifically about predonation costs related to the evaluation, which have been demonstrated to be significant (9). The prospective nature of the study allows examination of social relationship and financial changes following donation; however, given our naturalistic design, we cannot know that those factors caused changes in the outcome. Too few donors reported worsened relationships to explore predictors of these outcomes. Half of enrolled donors did not have 2-year data. Most did not reach that time point by study end and were administratively censored, implying missingness completely at random. Although some refused the survey, the similar findings from sensitivity analyses only among completers indicate that selection biases are likely minimal. We also noted high participant retention throughout the study.

## Future Directions

Gill et al found that the rate of kidney donation declined in the past 5 years specifically in the three lowest quintiles of U.S. incomes (33), reflecting the economic recession. In the two lowest quintiles, spousal donation also declined, perhaps reflecting the economic strain on households (33). Because financial resources may influence decision to donate, financial initiatives will need to include coverage of expenses beyond donation-related medical costs (31). National Living Donor Assistance Center (NLDAC) support is limited to travel and subsistence expenses and is subject to U.S. poverty definitions for donor and recipient household incomes. Transplant programs should emphasize the duration of recovery so donors have a realistic appreciation of potential donation-related costs. Donors may require more assistance with fundraising or other strategies to obtain predonation financial support. Donors should be prepared for unexpected financial burdens that can strain finances, particularly for those who travel greater distances to the transplant program and those with lower household incomes who may also miss work (10). Pilot projects to educate donors, to remove disincentives and possibly to expand resources such as NLDAC are suggested as

important first steps (34). Projects targeting those who are most financially vulnerable are needed.

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## Disclosure

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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**Supporting Information**

Additional Supporting Information may be found in the online version of this article.

**Table S1:** Donor–recipient interactions over time.

**Table S2:** Types of nonmedical costs over time.

**Table S3:** Financial outcome characteristics over time by Canadian versus U.S. donors.