Living-Donor Follow-Up Attitudes and Practices in U.S. Kidney and Liver Donor Programs

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Background. Although U.S. transplantation programs must submit living-donor follow-up data through 2 years after donation, the submissions have high rates of incomplete or missing data. It is important to understand barriers programs face in collecting follow-up information.

Methods. Two hundred thirty-one programs performing living kidney donor (LKD) and/or living liver donor (LLD) transplantation were contacted to complete a survey about program attitudes concerning donor follow-up, follow-up practices, and barriers to success.

Results. Respondents representing 147 programs (111 with only LKD and 36 with both LKD and LLD) participated. Sixty-eight percent of LKD and 83% of LLD respondents said that achieving follow-up was a high priority. The majority agreed that donors should be followed at least 2 years (61% LKD programs and 73% LLD programs), and sizeable percentages (31% LKD and 37% LLD) endorsed 5 years of follow-up. However, approximately 40% of programs lost contact with more than 75% of their donors by 2 years after donation. Follow-up barriers included donors not wanting to return to the program (87%), out-of-date contact information (73%), and lack of program (54%) or donor (49%) reimbursement for follow-up costs. Whereas 92% of LKD and 96% of LLD programs inform potential donors about follow-up requirements, fewer (67% LKD and 78% LLD) develop plans with donors to achieve follow-up.

Conclusions. Most respondents agree that donor follow-up is important, but they report difficulty achieving it. Improvements may occur if programs work with donors to develop plans to achieve follow-up, programmatic standards are set for completeness in follow-up data reporting, and sufficient staff resources are available to ensure ongoing postdonation contact.

Keywords: Living-donor follow-up, Kidney, Liver, Attitudes, Practices.

(*Transplantation* 2013;95: 883–888)

The transplant community is mandated to promote and monitor the safety of living-donor organ transplantation (*1*). In particular, the collection of follow-up information on donors' health status is crucial for understanding the risks and consequences of donation. This information is important not only for the care of individual donors, who may require timely intervention should health problems be revealed during follow-up, but also for the education of potential donors so that they can make informed decisions about whether to donate (*2, 3*).

For these reasons, it has been suggested that living-donor transplantation programs in the United States

The collection of survey data and portions of the data analysis for this work were supported by the U.S. Health Resources and Services Administration contract 234-2005-370011C to United Network for Organ Sharing for work conducted for the Organ Procurement and Transplantation Network Living Donor Committee. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

J.L.W. and L.B. are employees of the United Network for Organ Sharing. All other authors have no conflicts of interest to disclose.

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Supplemental digital content (SDC) is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal's Web site (www.transplantjournal.com).

Received 24 September 2012. Revision requested 18 October 2012.
Accepted 6 December 2012.

ISSN: 0041-1337/13/9506-883
DOI: 10.1097/TP.0b013e31828279fd

routinely inform potential donors about the "benefit and need for follow-up" after the donation surgery (*4*). Moreover, under policies developed to promote donor safety, living-donor programs must submit living-donor follow-up (LDF) forms to the Organ Procurement and Transplantation Network (OPTN)/United Network for Organ Sharing (UNOS) at hospital discharge or 6 weeks after donation (whichever is earlier) as well as at 6 months, 1 year, and 2 years after donation (*5*). Medical data to be reported on these forms include donor death, laboratory values (e.g., serum creatinine for kidney donors and bilirubin level for liver donors), and the development of specific medical conditions (*5, 6*).

Although donor program compliance with LDF form submission is extremely high, submitted forms often show that large percentages of donors (up to 100% in some programs) have been lost to follow-up (*7*). As a result, national follow-up data remain too incomplete to allow meaningful analysis of any trends in donors' health status (*2, 3, 6, 8*). A previous study reported that barriers to LDF among living kidney donor (LKD) transplantation programs include insufficient reimbursement for follow-up care and difficulty having donors return to the transplantation program (*9*). However, because fewer than half of all programs participated in this earlier effort, it is not clear whether these concerns generalize to all LKD programs. Moreover, to our knowledge, no research has examined practices and barriers to living liver donor (LLD) follow-up. Thus, in the present study, we contacted all LKD and LLD transplantation programs in the United States to survey their attitudes, ideal and actual follow-up practices, barriers to successful follow-up data collection, and suggestions for strategies to improve follow-up nationally.

RESULTS

Survey Respondents

The survey was sent to 231 transplantation programs, including 179 performing only LKD transplantation and 42 performing both LKD and LLD (Fig. 1). We received 115 surveys from programs performing only LKD and 39 surveys from programs performing both procedures. For a few programs, we determined that more than one survey had been submitted, as explained further below. After discarding these "extra" surveys, 111 LKD-only programs and 36 LKD/LLD programs were included in our sample for a total of 147 (response rate: 147/231 programs performing LKD=64% and 36/42 programs performing LLD=86%). The 147 surveys were submitted by transplant administrators/directors (61%), transplant coordinators (16%), independent donor advocates and living-donor coordinators (6%), data coordinators (5%), or other personnel (5%).

We identified seven cases in which multiple surveys were received from programs (Fig. 1). We identified these cases because, although we had informed respondents that they were not required to disclose their program's name, the majority of respondents (64%) named their program. For programs for which multiple surveys were received, we retained the survey from the transplant administrator or most senior program member for analysis.

Attitudes and Perceived Barriers for Living-Donor Follow-up

Table 1 summarizes respondents' endorsement of benefits and barriers to collecting LDF data. The most frequently endorsed benefits were improved risk information for prospective donors and improved knowledge about donors' health. The most common barriers were that donors did not want to return to the program for medical tests and donors' contact information became outdated. Lack of reimbursement to programs and to donors for follow-up costs were also endorsed relatively frequently.

Table 2 shows that, although the vast majority of respondents thought the OPTN should track donors' physical health, there was more variability in views about other factors to be tracked. Nevertheless, the majority felt that donors' psychologic well-being, disability and employment status, and insurance status should be monitored. Concerning parameters specific to LKD and LLD, large percentages of respondents endorsed serum creatinine and blood pressure tracking for kidney donors and total bilirubin, alanine aminotransferase, and aspartate aminotransferase tracking for liver donors.

Achieving 2 years of LDF was a high or extremely high priority for the majority (68%) of the 147 respondents with

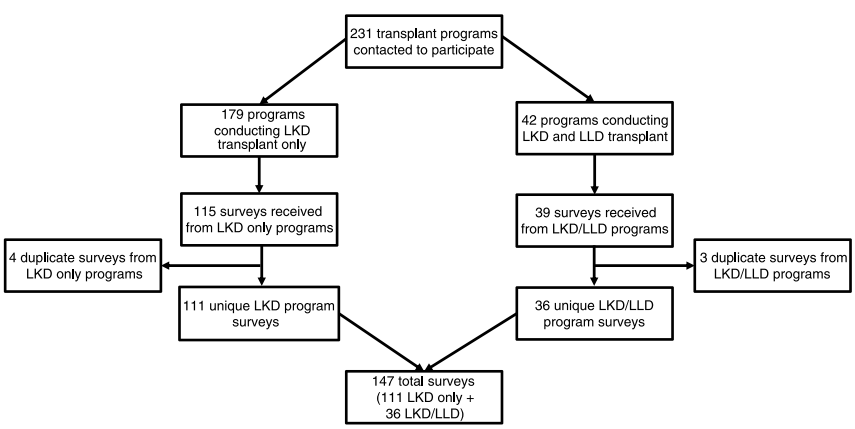

FIGURE 1. Flow chart of study survey accrual and inclusion in final sample.

TABLE 1. Benefits and barriers to collecting LDF data

	% Respondents (n=147)
Benefits	
Improved information can be provided to prospective living donors about risks	94.8
Improved knowledge about health of living donors in their program	94.7
Improved national trust in the process of living donation	85.0
Improved donation outcomes for future living donors	86.5
Improved health for living donors nationally	86.1
Reduced medical risks associated with kidney donation	70.2
Reduced medical risks associated with liver donation	78.8
Barriers	
Donors do not want to return to the transplantation program for medical tests as time passes	86.8
Living donors' contact information becomes outdated	72.7
Lack of reimbursement to programs for LDF costs	53.7
Lack of reimbursement to donors for costs associated with follow-up	48.8
Cost of additional medical testing for living donors	45.5
Living donors do not want to be contacted	38.8
Lack of staff time to follow-up with or locate living donors by telephone	35.5
Lack of staff time to conduct ongoing medical assessments of living donors	28.1
Lack of staff time to complete OPTN LDF forms	19.8
Other barriers	11.6

LDF, living-donor follow-up; OPTN, Organ Procurement and Transplantation Network.

LKD programs, whereas 20% said it was a moderately high priority and 12% said it was a low priority. Among the 36 respondents with LLD programs, the analogous percentages were 83%, 17%, and 0%. For respondents from programs performing both LKD and LLD, we could directly compare their attitudes on this issue for one type of donor versus the other. Although the between-group differences were not significant given the sample size (McNemar-Bowker χ^2=5.47[1]; df=3; P=0.14), there was a trend wherein respondents saw 2 years of follow-up as a higher priority for liver than kidney donors (83% vs. 70% endorsing high/extremely high priority).

Ideal and Actual Living-Donor Follow-up Practices

Respondents' opinions varied concerning how long a donor's health should ideally be monitored postdonation, with 31% of LKD respondents endorsing 5 years or more, 30% endorsing 2 years, 32% endorsing 1 year, and 8% endorsing 6 months or less. Of the LLD program respondents, the analogous percentages were 37%, 37%, 20%, and 7%. For respondents from programs performing both LKD and LLD, there was little difference in opinions about optimal follow-up duration by type of donor (LKD: 33% endorsing ≥5 years, 30% for 2 years, 27% for 1 year, and 9% for ≤6 months; LLD: 37%, 37%, 20%, and 7%, respectively; McNemar-Bowker χ^2=1.73; df=4; P=0.79).

Concerning current practices, most respondents said that their programs informed potential donors that 2 years of LDF was required (92% of LKD respondents and 96% of LLD respondents) and explained its importance (98% LKD and 93% LLD). However, fewer explained who was responsible for LDF costs (81% LKD and 78% LLD) or developed specific plans with potential donors for achieving LDF (67% LKD and 78% LLD). Among the 36 programs performing both LKD and LLD, responses did not differ by type of transplantation (all P's>0.05).

Respondents were asked what percentage of donors their programs had been able to contact for LDF over the past 2 years (response choices: 1–25%, 26–50%, 51–75%, and 76–100%). For each OPTN-required reporting time point, the majority (i.e., over half) stated that they had been able to contact more than 75% of donors. However, those reporting this level of success declined with time postdonation: at 6 months, 81% of LKD program respondents reported contact with more than 75% of their donors. This dropped to 71% achieving this level at 1 year and 61% at 2 years. Analogous success rates for liver donors were 81% at 6 months, 81% at 1 year, and 62% by 2 years. Direct comparison of these rates among respondents with both LKD and LLD programs showed no significant differences at any time point (all P's>0.05).

Several questions focused on LDF form completion. First, to ensure accuracy, respondents reported that donor medical information was always (45%) or usually (29%) reviewed with the donor or donor's physician. Programs also always (40%) or usually (29%) requested that donors return for reevaluation when out-of-range laboratory values appeared.

Second, concerning the classification of donors as lost to follow-up, most respondents said that their program would do so if donors could not be located through any information the donors originally provided (e.g., recipient contact information; 86%), if donors were called multiple times without a response (76%), or if donors could not be

[1] Because McNemar's test requires that no marginal cells have zero frequencies, we collapsed the "moderately high" and "low" categories to calculate the test.

TABLE 2. Medical and psychosocial data important to collect in follow-up with living donors

	% Respondents
General physical/psychosocial outcomes (n=147)	
Physical health status	94.1
Psychologic well-being	66.7
New temporary or permanent disability	59.3
Donation regret	51.9
Unanticipated change in donor–recipient relationship	28.1
Insurance/employment issues (n=147)	
Donor's ability to return to work	68.1
Difficulty obtaining health insurance	68.1
Loss of insurance	54.1
Unexpected out-of-pocket donation costs	53.3
Insurance not covering donor expenses as expected	50.4
Difficulty obtaining life insurance	48.9
Job loss	35.6
Health parameters for kidney donors (n=147)	
Blood pressure	91.6
Serum creatinine	95.4
Development of hypertension	74.8
Urine protein	67.9
Urinalysis	62.6
Weight	45.0
Urine protein-creatinine	43.8
New medications	42.0
Fasting blood glucose	35.1
Fasting lipid profile	9.2
Waist circumference	3.8
Health parameters for liver donors (n=36)	
Total bilirubin	93.3
Alanine aminotransferase	90.0
Aspartate aminotransferase	86.7
Serum albumin	80.0
International normalized ratio	76.7
Blood pressure	56.7
Serum creatinine	53.3
Fasting lipid profile	30.0
Fasting blood glucose	30.0

located using Internet telephone databases (54%). If donors were reported lost at one time point, 49% would not attempt to locate them at subsequent time points.

Third, concerning data recording, respondents were asked what laboratory values, if any, were recorded on LDF forms when donors were lost to follow-up. Although 54% indicated that no values would be recorded, 29% reported that the last known values from the medical record would be entered.

Fourth, concerning costs incurred collecting LDF information, most respondents endorsed costs associated with staff time to complete LDF forms (99% LKD and 96% LLD), staff time to contact donors (97% LKD and 96% LLD), staff time to conduct donor medical assessments (85% LKD and 96% LLD), and medical test costs (76% LKD and 79% LLD).

Strategies for Improvement of Living-Donor Follow-up

Respondents were asked whether their program would be willing to pay a third party to collect and submit required LDF data; most (76%) were unwilling to do this. Respondents' open-ended suggestions for improving LDF reflected three themes (Table 3): (a) overcoming LDF financial barriers (e.g., by providing financial compensation to programs for required follow-up), (b) increasing living-donor cooperation (e.g., by reimbursing donors), and (c) improving accuracy of LDF (e.g., through reducing programs' reporting requirements).

DISCUSSION

Tracking living donors' health and psychosocial outcomes has potential advantages for living-donors and the transplant community at large (*2, 3, 6*). A comprehensive, national database of 2-year living-donor outcomes may improve understanding of donation risks and may enable the transplant community to detect and intervene with any donors experiencing adverse events from donating. It may contribute to more data-driven process improvement activities for LDF at both national (OPTN) and program levels. Our examination of 147 respondents at the majority of U.S. programs performing LKD and/or LLD transplantation revealed that, in theory, programs want follow-up to assess living-donors' outcomes for at least 1 to 2 years after donation, with more than 30% of respondents considering that the 2 years mandated by OPTN is not long enough. However, respondents acknowledge difficulty completing LDF; approximately 40% report that their programs have lost the majority of donors to follow-up 2 years after donation.

Unique to our study is the examination of attitudes and practices for follow-up in LLD programs. Liver donation clearly has higher risks than kidney donation (*10, 11*). Although some respondents reported that LKD follow-up was not a program priority, all respondents with LLD programs reported that follow-up of these donors was a priority, and most declared it to be a high to extremely high priority. Respondents felt that the minimum required follow-up should be longer for liver than kidney donors, with many wanting 5 years or more of follow-up. Moreover, consistent with analyses of LDF form data collected by OPTN (*7*), respondents reported greater success in liver than kidney programs in following the majority of their donors, at least through 1 year after donation.

Given the priority that programs place on follow-up, what activities are they undertaking—or failing to undertake—that would maximize follow-up rates and data quality? Important strategies include discussing and planning for LDF with donors before donation. We found that, although the vast majority of programs inform potential donors of LDF requirements, fewer programs discuss with them who will be responsible for LDF costs or develop specific plans with donors to achieve follow-up. From the list of potential barriers to LDF included in the survey, some of the barriers endorsed (e.g., outdated donor contact information) also suggest that programs may be failing to

TABLE 3. Suggestions to improve living donor follow-up from open-ended questions

	% Respondents (n=76)
Overcoming financial barriers	
Medicare should cover the 2 years of follow-up	32.9
Recipient's insurance should cover the 2 years of follow-up	30.3
Governmental agencies requiring follow-up should cover the 2 years of follow-up (e.g., HRSA and Centers for Medicare and Medicaid Services)	10.5
Reimburse programs for follow-up (no funding source specified)	9.2
Donors should only be accepted if they have insurance	2.6
Programs should be reimbursed based on the completeness of their forms	2.6
Increasing donor cooperation	
Reimburse or incentivize donors for follow-up (e.g., tax deduction, coupon for required medical care, and payment as in research studies)	19.7
Donors should complete surveys by mail	11.8
Donors should be better educated about why follow-up is important	11.8
Donors should self-report data using a national online system	10.5
Donors should be required to sign a contract mandating their compliance with follow-up	6.6
Donors should cooperate with programs for follow-up; it is for their own benefit	3.9
Improving accuracy of follow-up procedures	
Reduce data requirements to the basic tests, with extra tests required only if basic tests are abnormal	19.7
Patients' local primary care provider should conduct follow-up tests	15.8
A national organization should take responsibility for obtaining results of follow-up tests (e.g., UNOS and National Living Donor Assistance Center)	9.2
Publish clearer information to physicians about what is required for follow-up and billing (e.g., correct tests to perform)	9.2
Reduce follow-up to 1 year; more is unnecessary	6.6
Stop penalizing for late/incomplete data	6.6
There should be designated staff for this task	5.3

HRSA, Health Resources and Services Administration; UNOS, United Network for Organ Sharing.

fully use strategies to maximize the likelihood that donors will be reached at the required LDF time points. Thus, numerous Internet resources are available at no cost to identify individuals whose contact information is inaccurate and simple approaches (e.g., asking donors predonation for the name of someone who will always know where they are) can also be helpful (*6, 12*). Moreover, when donors are lost, national data are incomplete or, as our survey responses suggest, potentially inaccurate. For example, we found that respondents from nearly one third of programs would report the last known laboratory values on LDF forms when living donors were lost to follow-up, irrespective of when those values were obtained. This is disconcerting, because reporting out-of-date medical data could mask true levels of postdonation risks.

High rates of LDF are possible; a lengthy series of recommendations have been developed based on practices used by programs with among the highest rates of LDF nationally (*6, 12*). However, our survey corroborated previous research focused on LKD programs (*9*) in identifying two critical barriers to complete follow-up: lack of financial reimbursement to programs for LDF expenses and difficulty getting living donors to return for required medical tests. Our respondents suggested that LDF could be improved if its costs were reimbursed. Another innovative suggestion was that program reimbursement be based on LDF forms' completeness.

To ease living-donor burden for follow-up, respondents suggested having donors complete the tests with their primary care provider rather than returning to the transplantation program, allowing donors themselves to submit the results of local primary care follow-up, and incentivizing donors for follow-up with, for example, direct payments or tax reductions. Some such strategies (e.g., local primary care follow-up) are already accepted by the OPTN and are used by high-performing programs (*12*); others support and expand on suggestions in the transplantation literature and the literature on increasing participation in clinical trials (*8, 9, 13*).

Our study has limitations. First, although survey respondents represented the majority of U.S. LKD and LLD programs, our findings may not generalize to programs that did not participate. Moreover, we could not compare responders with nonresponders because respondents were not required to provide their program's name. Second, although we eliminated a few "duplicate" surveys (i.e., when multiple surveys were submitted per program), we could do this only when respondents provided their program's name. Because providing the name was optional, there may have been unidentified duplicates. However, the low rate of duplicates among named programs suggests that most programs submitted only one survey. Third, different types of program personnel completed the survey, and they may have varied in their knowledge of program practices.

Fourth, we could not compare survey responses based on patient demographics or other program characteristics because we did not collect such information. Finally, it is possible that the questions were answered to put programs in the best possible light. Although we did not require that respondents identify their program for just this reason, respondents may have believed that even surveys submitted without names could be traced.

In summary, improvements to the current OPTN/UNOS LDF data collection requirements may occur if living-donor programs not only view LDF as essential but also inform and plan for LDF with donors before donation. Moreover, setting programmatic standards for completeness and accuracy in data reporting may contribute to higher LDF rates. However, financial barriers are likely to limit both the quality and the duration of follow-up. Strategies to maximize cost-efficient LDF are essential (*3, 6, 12*). As donor characteristics and medical technologies change, only with complete LDF will we truly understand living-donors' health outcomes, take steps to ensure their continued safety, and ultimately maintain public trust.

MATERIALS AND METHODS

Survey Development

The research team, including experts in survey design and living donation, developed a 20-min Web-based survey consisting of a maximum of 50 items, with skip-out patterns as appropriate (i.e., items specific to LKD or to LLD were answered only by respondents whose programs performed both types of living-donor transplantation). (For the complete survey, see **SDC**, http://links.lww.com/TP/A777.) Several categories of questions were included. First, we asked 19 closed-ended questions about each program's perceptions of the benefits of LDF, what dimensions of donors' well-being should be tracked, what program practices for obtaining LDF information, and what barriers hindered follow-up. Second, depending on the type of living-donor transplantation performed in respondents' programs, they were asked 11 closed-ended items specific to LKD and 11 closed-ended items specific to LLD. These items included their views on the importance of conducting follow-up specific to LKD or LLD, what specific health measures should be tracked, how LDF was discussed with donors before surgery, what programs' LDF practices were, and what direct costs programs incurred. Third, respondents were asked one closed-ended and seven open-ended questions to elicit suggestions on how to improve LDF. Specifically, we asked for suggestions to increase the accuracy of LDF data reported to the OPTN, track and report donors' health more easily and at lower cost, increase reimbursement rates associated with LDF, and identify other sources of funding for LDF costs. Lastly, an optional item was included that asked the name of the respondent's transplantation program, if the respondent wished to provide it (but noted that this information was not required to submit the survey).

Survey items were prepared and reviewed by transplant administrators, physicians, and survey research experts on both the OPTN Living Donor Committee and the Transplant Administrators Committee to ensure items' clarity and relevance.

Participants and Procedure

Survey data collection was carried out under the exemption from institutional review board approval granted by U.S. Health Resources and Services Administration (HRSA) to the OPTN for its data collection activities. In early 2010, UNOS emailed an invitation to all primary transplant administrators, as identified in OPTN records, at U.S. transplantation programs that performed LKD and/or LLD transplantation, asking them to complete the survey or assign another representative responsible for LDF to complete it. To increase participation and honesty about potentially sensitive topics, survey instructions stated that respondents were not required to disclose the name of their transplantation program (and neither was their name requested). They were informed that if they chose to identify their program, this information would be kept confidential. Respondents entered their survey responses on a KeySurvey Web site.

Data Analysis

Descriptive statistics were calculated to examine general LDF questions for the entire sample and questions relevant to LKD or LLD follow-up specifically. For transplantation programs that performed both LKD and LLD transplantation, we compared responses for the two program types using McNemar chi-square tests. Respondent suggestions (from open-ended items, described above) were transcribed and reviewed by two authors trained in qualitative analysis (A.D.W. and M.M.). Suggestions consisted largely of brief phrases or lists. In keeping with these short-answer, list-type data, suggestions were grouped by the authors into categories that reflected similar themes, with discrepancies in category coding resolved through discussion between them until consensus was reached (*14*). Frequencies of providers reporting suggestions in each category of suggestion were calculated.

ACKNOWLEDGMENTS

The authors thank the members of the 2009–2011 OPTN Living Donor Committee and the Transplant Administrators Committee for their contributions to this study.

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