Donor Health Assessment After Living-Donor Liver Transplantation

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Objective
To elicit donor opinions on liver living donation through use of a survey that protected the anonymity of the respondent and to assay long-term (follow-up > 1 year) donor health by a widely recognized instrument for health assessment.

Summary Background Data
Living-donor liver transplantation is an accepted technique for children that has recently been extended to adults. Limited donor outcomes data suggest favorable results, but no outcomes data have been reported using an instrument that elicits an anonymous response from the donor or employs a widely recognized health survey.

Methods
Forty-one living-donors between June 1992 and June 1999 were identified and included in this study, regardless of specific donor or recipient outcome. Each donor received a 68-question survey and a standard McMaster Health Index.

Results
Survey response was 80%. All donors were satisfied with the information provided to them before donation. Eighty-eight percent of donors initially learned of living donation only after their child had been diagnosed with liver disease: 44% through the transplant center, 40% by popular media, 12% by their pediatrician, and 4% by their primary care physician. Physical symptoms, including pain and the surgical wound, were recurrent items of concern. Perception of time to “complete” recovery were less than 3 months (74%), 3 to 6 months (16%), and more than 6 months (10%). Donors’ return to physical activities was shown by above-mean McMaster physical scores; scores for social and emotional health were not different from population data. There were no reported changes in sexual function or menstruation after donation, and five of six donors procreated.

Conclusions
Donors overwhelmingly endorsed living donation regardless of recipient outcome or the occurrence of a complication. Eighty-nine percent advocated “increased” application of living donation beyond “emergency situations,” and no donor responded that living donation should be abandoned or that he or she felt “forced” to donate.

Living-donor liver transplantation (LDLT) is a universally accepted technique for the treatment of children with end-stage liver disease. Theoretically proposed by Smith in 1969¹ and initially reported by Raia et al.² and Strong et al.,³ a 10-year body of data has accumulated from Asia, North America, and Europe since the earliest series reported by Broelsch et al.⁴

The application of living donation has had a significant impact on pediatric organ wait-list times and decreased wait-list deaths.⁵ The theoretical advantages of “timing” liver transplantation as to avoid patient deterioration while awaiting a cadaveric graft, decreasing hospital stay by earlier transplantation, and the provision of “optimum” grafts that have received intense medical screening with minimal
ischemia times have been realized. Furthermore, the incidence of primary graft nonfunction in living-donor recipients is significantly less than that observed in cadaveric grafts.

Reports of pediatric LDLT donor outcomes have been equally satisfactory; however, no long-term donor outcomes data have been reported using an instrument that permits an anonymous response from the donor or that evaluates postdonation health by a widely recognized health survey. The objectives of this study were to elicit donor opinions on liver living donation through use of a survey that protected the anonymity of the respondent and to assay long-term (follow-up > 1 year) donor health by a widely recognized instrument for health assessment. To achieve these objectives, we designed a questionnaire on liver living donation and coupled the survey with a McMaster Health Index Questionnaire (MHIQ).

METHODS

All materials and protocols were reviewed and approved by the University of California San Francisco (UCSF) Committee on Human Research before initiation of this study (CHR#: H9048–14519–01). Inclusion criteria for this study were as follows: liver living donation performed at UCSF, donation of a left-lateral segment graft (Couinaud segments II and III), and follow-up greater than 1 year. Donors were included in the survey regardless of specific donor or recipient outcomes. The UCSF liver living donor survey consisted of 68 graded response-type questions categorized as follows: demographic (n = 11), donor evaluation (n = 8), application of living donation (n = 9), recovery from living donation (n = 31), postdonation complications (n = 6), and care provided at UCSF (n = 3). Graded response-type questions present a statement to which the respondent selects an answer that most closely matches his or her own.

The MHIQ is a widely recognized measure of quality of life and health that has been used to assess outcomes in a variety of patient populations. The MHIQ consists of 24 questions assessing physical health, 24 questions on social health, and 19 questions addressing emotional health.

Forty-one donors underwent LDLT between June 1992 and June 1999. From this group, 35 donors’ current addresses were available (4 were non-U.S. residents, 2 were lost to follow-up). After verification of present address, each donor received a liver living donor survey and a standard MHIQ with an unidentifiable return envelope. All data were scored by an independent observer.

RESULTS

Demographic Data

Twenty-eight donors returned our survey, yielding an overall response rate of 80%. The respondent population was principally parents donating to their child but did include an aunt donating to her niece and a son donating to his mother in an adult-to-adult living donation. All respondents underwent a left-lateral segmentectomy yielding a Couinaud segment II/III graft. Respondent ages at donation ranged from 19 to 49 years, with a median follow-up of 3 years. Donor educational level and medical and surgical histories as well as respondent demographic data are summarized in Table 1.

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* Excluding childbirth.  † Excluding cesarean section.

Donation Process

Eight questions addressed the process of living donation, including how donors initially learned of the option of LDLT, what their initial opinion was of LDLT, and how their opinion toward the process evolved as they proceeded through the donor evaluation. Eighty-eight percent of donors initially learned of the option of LDLT only after their child had been diagnosed with liver disease: 44% were
informed by transplant center staff, 40% learned of LDLT by popular media (television, newspaper, Internet), 12% were informed by their pediatrician, and 4% were informed by their primary care physician. Internet web sites and support groups such as the Biliary Atresia Support Group were the most frequently cited source of media information. All donors reported immediate interest in the option of living donation at the initial presentation of information, and most became “more interested” in living donation as they proceeded with their preoperative evaluation. The availability of living donation as a therapeutic option was identified by more than half of donors as a “principal” criterion in the selection of a transplant center.

Donors were also asked about the information provided to them by the transplant center before donation and their overall experience of LDLT. When donors were asked about the information provided to them by the transplant center before donation, 72% of donors “strongly agreed,” 16% “agreed,” 8% were “neutral,” and 4% “disagreed” with the statement, “I believe I was told everything I needed to know about the surgery before I made my decision to donate.” When asked to reflect on their experience, no donor regretted his or her decision to donate or felt “forced” to donate.

Application of Living-Donor Liver Transplantation

Nine questions were devoted to donor views on the application of LDLT. Donor attitudes toward the role of LDLT were uniformly positive, with a large majority advocating increased use of LDLT as a potential solution to the current shortage of donor organs. Eighty-nine percent of donors replied that the role of LDLT should be “increased,” whereas 12% responded that LDLT should be reserved only for an “absolute emergency” or as an “absolute fast resort.” Ninety-two percent of donors “strongly agreed” with the statement, “I would recommend living donation to a parent who has a child in need of a liver transplant,” and every donor strongly disagreed with the statement, “I believe living donation should be outlawed/abandoned.”

Postdonation Recovery

Assessment of postdonation recovery was the largest component of our survey, with 31 questions devoted to recovery at home, return to work, and long-term sequelae from LDLT. When asked to compare their actual recovery period to what their expectations were before the donation, responses were as follows: 46% “faster than expected,” 16% “expected,” and 38% “slower than expected.” Donor perceptions of a prolonged recovery period were further evident when asked to estimate their time to “complete” recovery, as 26% reported a recovery time of less than 1 month, 48% reported within 1 to 3 months, but 26% required a recovery period of greater than 3 months and 5% required greater than 12 months to complete recovery.

Donor physical symptoms, including pain and the appearance of the surgical wound, were recurrent items of concern, particularly in patients with no previous history of surgery. Donors frequently commented on postdonation pain, even with the universal use of epidural analgesics and patient-controlled anesthesia. Forty-four percent of all donors reported postoperative pain “greater than anticipated,” only one third reported “less than expected” postoperative pain. Differences in reported pain were noted between donor sex and history of previous surgery. Concern over donor pain remained a significant complaint among female donors with a past surgical history, whereas male donors with a past surgical history appeared to report less postoperative pain; however, the number of respondents was too small to draw conclusions.

The surgical wound was a frequent comment from donors. Our donor procedure is routinely performed through a midline incision. When asked about their surgical wound, 28% of all donors reported a surgical wound that was “worse than expected” and 44% reported a wound that was “better than expected.” Individual analysis of donors by sex and previous surgical history revealed an approximately 25% incidence of donors who consistently reported a surgical wound that was worse than expected. With respect to postdonation physical appearance, two thirds of all donors responded that the surgery made “no change” in their physical appearance. Satisfaction with postdonation physical appearance remained high regardless of donor sex or prior history of surgery.

Return to employment is a significant consideration in the decision to proceed with living donation. Accordingly, our survey devoted multiple questions to the recovery process with respect to return to employment and predonation employment activities. Since donation, 79% of donors had returned to their predonation employment, 16% had changed their employment, and 5% had become unemployed. Time to return to employment was less than 1 month (10%), 1 to 3 months (52%), 3 to 6 months (22%), 6 to 12 months (12%), and more than 12 months (4%). All donors who returned to work were able to resume the same employment activities as before donation, responding, “I do the same activities I used to do before the surgery.” No donor required disability as a result of living donation, and all donors who had changed employment or who had become unemployed reported their change in employment was not the result of the living donation.

In addition to return to work and household activities, postdonation reproductive function was assessed by gender-specific as well as gender-specific questions. Ninety percent of male and female donors reported no change in sexual desire, performance, or activity after living donation. Furthermore, 70% of donors “strongly disagreed” and 30% were “neutral” to the statement, “The surgery of living
donation has diminished my desire to have additional children.”

Menstrual history before and after donation was specifically addressed in female donors. There was no change in the response of female donors with respect to menstrual history before and after donation. Postdonation sexual dysfunction was assessed in male donors by seven gender-specific questions addressing impotence and sexual performance. Male donors uniformly denied postdonation impotence as well as any change in sexual performance. Six donors (three men, three women) have attempted to have additional children since the donation, and five of the six have procreated (one female donor has been unsuccessful).

**Postdonation Complications**

A decade of experience with pediatric LDLT indicates donor outcomes have been excellent. Grewal et al. and Yamaoka et al. have reported outcomes of at least 100 LDLT donors, with findings of donor hospital stay routinely less than 10 days, average donor blood loss less than 500 mL, and rare requirements for heterologous blood transfusion. Their data have been mirrored by smaller studies in Asia, North America, and Europe. The overall incidence of reported donor complications is approximately 15%, with roughly half classified as serious (requiring either a surgical or interventional procedure or increasing hospital stay) and half classified as nonserious.

Our donors reported an overall postdonation complication rate of 28.6%. Reported complications included three complaints of new-onset dyspepsia, two parenchymal bile leaks, one incisional hernia, one wound infection, and one partial bowel obstruction. We are not aware of a complication occurring in any donor who was not included in this study (four foreign nationals and two donors lost to follow-up). Of note, the donors’ reported complication rate was higher than our recognition of donor complications. Further, each donor who had a complication reported that his or her transplant physician had identified the complication and discussed treatment options with them, suggesting a bias in underreporting of complications by the transplant team. More than half of our reported donor complications resulted in prolonged hospital stay as a result of interventional radiologic procedures, increased observation, intravenous antibiotics, or future elective surgery.

Although we recognized complications requiring an increased length of hospital stay, our failure to report symptoms that donors reported as complications were primarily in postdonation dyspepsia and altered gastric motility. Postdonation dyspepsia/ altered gastric motility is a phenomenon that has been poorly documented in the literature but likely occurs more frequently than reported. The left vagal trunk sends branches from the stomach to the hepatic hilum through the gastrohepatic ligament. In pediatric LDLT, this ligament is divided during the dissection and the stomach and diaphragm are retracted, creating the potential for vagal injury. We surveyed our donors for the occurrence of postdonation dyspepsia/ altered motility by including a question on postdonation diet patterns. Eleven percent of responding donors reported symptoms of dyspepsia by answering that there were certain foods that they avoid since the donation. Two reports document postdonation dyspepsia in previously healthy donors; in this report, we observed this complaint in three donors and have successfully treated these symptoms with H2-antagonists.

Donors who experienced a complication remained positive with respect to the procedure; however, comparison of donors who experienced a complication with donors who did not experience a complication revealed differences in opinion toward the application of LDLT. Donors who experienced a complication endorsed LDLT, as evidenced by their continued recommendation of the procedure and 86% response that LDLT should be “increased.” However, donors who experienced a complication did not exhibit the same enthusiasm for LDLT outside emergency settings as did donors who did not experience a complication. To the statement, “I believe people should donate a part of their liver only as a last resort when all other possibilities have failed,” 71% of donors who did not experience a complication disagreed, versus 37% of donors who experienced a complication. Similar reservations among donors who experienced a complication were observed in questions that prompted donors to recommend LDLT outside the settings of “absolute last resort” or “absolute emergency.”

**McMaster Health Index Results**

A principal objective of this study was to assess long-term postdonation donor health by a widely recognized health survey. The MHIQ is an instrument designed to evaluate quality of life and health. The MHIQ has satisfied reliability and validity testing as a measure of global health and observed performance in a variety of patient groups, in different patient settings, and by various health professionals. Further, it has been widely used to compare quality of life between populations with various illnesses and healthy populations, thereby permitting comparison of our donor responses to population norms.

The MHIQ is subdivided into three independently scored categories: physical, social, and emotional health. The physical component evaluates physical activities, mobility, self-care activities, communication, and global physical function. The social component includes general well-being, work/social role performance, material welfare, family support/participation, friends support/participation, and global social function. The emotional component assesses self-esteem, attitudes toward personal relationships, thoughts of the future, critical life events, and global emotional function. A distinct advantage of the MHIQ for use in our survey is the instrument’s assessment of actual performance by the respondent, rather than the capacity for functioning.

Postdonation donor health assessment is summarized in
Table 2. Donor health scores were highest in the physical category with a mean, mode, and range equal to or higher than scores observed in healthy populations. Higher observed physical scores may represent medical selection bias in the donor evaluation process or age bias in the selection of donors who are predominantly parents of affected children. Social and emotional performance scores within the donor group were not different from population norms in other studies. Notably, the greatest variation was observed among emotional scores, which is also observed within population norms and general medical patients.

Recipient Outcomes

Recipient outcome has been shown to affect postdonation donor attitudes toward donation in kidney living donors. To survey our population on recipient outcomes, two questions assessed recipient outcomes and how recipient outcomes compared with the donor’s expectation of recipient outcome. Eighty-one percent of responding donors reported their recipients were currently healthy; 12% responded their recipient remains ill. Six responding donors reported loss of the living-donor graft, and two responding donors lost their recipient (one at surgery and one at 6 months after LDLT). As for donors’ expectation of recipient health after the donation, 88% of donors reported the recipient’s health was “better than expected.” Although the number of donors who lost their donated graft or experienced a recipient death was too low to draw conclusions, their responses were no different from those of donors who experienced an optimal outcome.

DISCUSSION

Excellent data from North America, Asia, and Europe showing long-term patient and graft survival rates from pediatric LDLT have established this procedure as an accepted therapeutic option for the treatment of children with end-stage liver disease. As the worldwide experience with LDLT has increased, objective data on long-term donor outcomes and attitudes toward the procedure remain sparse. The purpose of this investigation was to elicit donor opinions of liver living donation through use of a survey that guaranteed the anonymity of the respondent and to assay postdonation donor health by an independent, widely accepted measure of quality of life. Our intent was to elicit data that could be used to further educate and inform potential donor candidates.

Although the conclusions of this study are limited by a relatively small population comprised principally of parents who experienced overall excellent results, our data indicate donor endorsement of LDLT with a majority advocating increased application of the procedure beyond the situation of a medical emergency. Endorsement of LDLT was acknowledged by donors regardless of recipient outcome, graft outcome, or the presence of a postdonation complication. No donor responded LDLT should be abandoned or they felt “forced” to donate, and all donors were satisfied with the information provided to them before the donation.

Complete return to predonation activities at home and at work was observed in all donors and verified by above-mean MHIQ physical scores. Despite a complete return to health, donor physical symptoms, particularly postsurgical pain and the appearance of the surgical wound, were recurrent items of concern. Interestingly, 37% of donors reported “greater than expected” pain despite our concerted effort to minimize postoperative pain with epidural anesthesia and patient-controlled analgesia. Donor reports of pain were also a frequent finding among adult-to-adult LDLT donors in a large series by Marcos et al.

With respect to the surgical incision, we have abandoned a subcostal incision in favor of a midline incision for pediatric LDLT and specifically show the potential incision to all candidates. Other physical parameters, including sexual function and menstruation patterns, were not affected by living donation; five of six donors attempting to have children procreated.

Donor perception of time to “complete” recovery was longer than expected, with roughly one quarter of donors requiring greater than 3 months and 5% of donors requiring greater than 1 year to achieve “complete” recovery. Before obtaining this data, our center historically informed donors to expect complete recovery within 3 months; however, our current practice is to share these data with donor candidates and educate them about the possibility of a prolonged recovery period.

Although multiple reports suggest average donor hospital stays of less than 7 days and the performance of living donation without the need for nonautologous blood transfusions, the performance of LDLT is not without significant risk. The overall incidence of donor complications reported from multiple centers has ranged from 10% to 15%; complications include hemorrhage, pulmonary embolus, biliary injury, hernia, postoperative bowel obstruction, and sepsis. Further, deaths from donation of the left-lateral segment have occurred. We previously reported five complications in the study donor pool, yielding an overall complication incidence of 14%; however, analysis of our donor responses suggested that we overlooked symptoms that donors attributed to a complication. Twenty-eight per-
cent of our responding donors indicated they had a complication related to LDLT, a value twice as high as we expected. This observation suggests the overall incidence of donor complications may be inadvertently underreported by transplant physicians.

Postdonation donor health and quality of life have been addressed in long-term, large cohort studies of kidney living donors, and several observations from these studies have been reflected in our limited survey. Simmons et al.27 were the first to report on long-term follow-up of kidney donor quality of life at the University of Minnesota. In their seminal study, a majority of kidney living donors reported enhanced self-worth and expressed a willingness to donate again. These authors’ finding of enhanced self-esteem after donation was confirmed in larger studies with a longer follow-up.28,29 In a mail survey of 536 kidney living donors, Smith et al.30 reported that 96% of donors reaffirmed their decision to donate regardless of recipient outcome, with a majority of donors reporting a complete return to predonation activities; permanent disability was extremely rare. Johnson et al.,24 in a survey of 524 kidney living donors who underwent donation between 1984 and 1996, reported donor group scores that exceeded the national norm on the SF-36, a standardized quality of life and health questionnaire. Although our survey did not specifically address postdonation donor self-esteem, donors were overwhelmingly positive toward the process of living donation, with a majority reporting complete recovery and an overall experience they would recommend to others. Further, their MHIQ physical scores exceeded national norms and their emotional and social scores paralleled national norms.

Although most reports on kidney living donation suggest an improved relationship with the recipient and a generally positive donor experience, postdonation depression, disrupted family life, and donor suicide related to poor recipient outcome have been reported.24,31–33 Multivariate analysis to identify risk factors associated with donor dissatisfaction, a poor psychosocial outcome, or donor regret for the decision to donate indicated that relationship to the recipient and recipient outcome were the only variables associated with donor dissatisfaction.24 Specifically, relatives other than first-degree donors whose recipient died within 1 year after donation were more likely to say they would not donate again. In addition, parents who donated to their children consistently showed the highest level of satisfaction, whereas donors who were unrelated to the recipient showed the highest level of dissatisfaction.24 Johnson et al.24 suggested that this observation should warrant extensive psychosocial evaluation by the transplant team as to the precise expectations and motivations of unrelated donor candidates or donor candidates who are not first-degree relatives.24

The limitations of the current study are apparent and underscore the need for more extensive studies on nonparental pediatric liver living donors and adult-to-adult living donation, as this relatively new procedure draws largely from a nonparental, extended-relative population.

Donor feelings of abandonment by the medical staff after the donation have also been reported among kidney living donors,24 and we have heard at least three of our donor candidates express similar feelings during follow-up appointments. This led to a concerted effort to address such feelings during the routine postoperative care of our donors.

The decision to donate is frequently spontaneous in both kidney and liver living donors. Smith et al.30 reported that 93% of parental kidney donors and 70% of overall kidney donors volunteered for donation without solicitation; our data indicate that a similar majority of liver living donors embraced the concept of living donation when initially presented with this option. Both donor groups were satisfied with the data presented to them regarding living donation, with over 80% of kidney living donors30 and all our liver living donors indicating they had received adequate preoperative information.

Lastly, the principal role of the transplant team as the source of living donor information was previously recognized in kidney donation. The transplant team was most frequently identified as the principal source of living donor information in our study, as in Smith et al.,30 with primary care physicians identified as principal informants in only 10% of kidney donors and a similarly small 5% of our liver living donors. The observations of only 12% of donors aware of LDLT before their recipient was diagnosed with liver disease, 40% of donors initially learning of LDLT through a media source, and 52% expressing the potential of LDLT as a principal criterion in selecting a transplant center suggest the transplant community must effect increased awareness of the potential for liver living donation among unaffected individuals as well as primary care and nontransplant physicians.

Our data suggest overall donor satisfaction with the performance of pediatric LDLT; however, these results may not be directly applicable to the performance of adult-to-adult LDLT because of the wider spectrum of donor candidates and vastly different surgical procedure. This preliminary report attempted to survey fundamental issues in the process of living donation, and it is apparent that the results require validation and expansion through larger studies involving multicenter or national pediatric and adult living donor registries. The inclusion of additional topics such as the financial hardship incurred by living donation, familial interactions after the donation, the emotional stress of the donation process, and the availability and cost of life and health insurance in larger registry studies would be particularly relevant.

References


