

Outcomes in Living Liver Donor “Heroes” After the Spotlight Fades

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Sports and military heroes frequently receive extensive public praise and admiration for their exceptional performance and acts of bravery. In that vein, an individual who donates a part of their liver to a family member or close friend is a medical “hero” to the recipient as well as to the broader community. Living liver donors (LLDs) voluntarily agree to incur substantial personal risk (ie, mortality of 1 in 250 to 1 in 500) in an effort to help a fellow human being in dire need of a lifesaving liver transplant. Not surprisingly, living liver and kidney donors have a higher level of resilience and perseverance to overcoming adversity when compared with population controls.⁽¹⁾ Although liver donors experience significant postoperative pain and up to 3 months of functional disability and lost wages, they are not financially incentivized nor recognized for their good deed. However, the majority of living donors are rewarded by their sense of self-fulfillment and gratification that persists for many years after donation.⁽²⁾

Because the annual number of adult-to-adult living donor liver transplantations (LDLTs) is limited, the frequency, type, and severity of complications among donors are not well known nor are the donor or

recipient features associated with adverse outcomes. Medical risks within the first year of donation include biliary complications (20%), infections (20%-30%), and the need for reoperation (5%-10%).^(3,4) In addition, there are rare reports of severe psychiatric complications in adult liver donors that may occur remotely from transplant.⁽⁵⁾ In this issue of *Liver Transplantation*, investigators from New York help improve our understanding of the longterm health and functional outcomes of adult LLD.⁽⁶⁾ The data in this study arose from a statewide quality-assurance effort that was initiated in New York in 2004 and included the development of a liver donor-specific questionnaire to assess 7 quality-of-life domains.

The 220 liver donors in the current report expand our understanding of functional outcomes previously reported by the Adult-to-Adult Living Donor Transplantation Cohort Study⁽²⁾ and from Toronto⁽⁷⁾ (Table 1). Notable strengths of this multicenter report include the high rate of eligible participant involvement over 6 years (70%) and the ability to extract new issues and concerns over time by a combination of multiple choice and open-ended telephone survey questions. Study limitations included the lack of baseline donor psychosocial profiles, information regarding the type of LLD performed, and recipient outcomes, which could significantly impact donor views and perceptions. Furthermore, the lack of a paired comparison of individual patients over time could have substantially underestimated the frequency and severity of complications. Nonetheless, the majority of LLD reported high rates of willingness to donate again (>90% through year 5 after donation), feeling “very satisfied” after donation (81%-88% over time), and an increased positive outlook and self-worth related to LLD (82%). Interestingly, all of this positivity occurred in a cohort that also incurred substantial financial expense with 12% having spent more than US \$3000 for LLD-related expenses and 8% reporting that donation was a major financial hardship for them. In addition, 28% reported abdominal incisional pain negatively impacting their quality of life, and 21%

Abbreviations: HRQOL, health-related quality of life; LDLT, living donor liver transplantation; LLD, living liver donor; LOS, length of stay; MCS, mental component summary; SF-36, Short Form 36.

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Received March 25, 2019; accepted March 25, 2019.

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View this article online at wileyonlinelibrary.com.

DOI 10.1002/lt.25459

Potential conflict of interest: Nothing to report.

TABLE 1. Studies of Longterm Outcomes in Adult LDLT Donors

	LaPointe Rudow et al. ⁽⁶⁾ (2019)	Dew et al. ⁽²⁾ (2016)	Adcock et al. ⁽⁷⁾ (2010)
Study Characteristics			
Description	Qualitative methods LLD-specific questionnaire Multicenter, prospective longitudinal, and quantitative	Multicenter, cross-sectional telephone survey	Chart review Detailed medical, single-center, retrospective, and psychosocial data
Population (years of data)	5 centers in New York (2004-2013)	9 North American centers (2002-2009)	Toronto (2000-2008)
Number of participants, n (%) [*]	220 (72%)	517 (66%)	202 (82%)
Age at donation, years, median (range)	41 (20-62)	Not reported (19-61)	37 (18-60)
Sex, female	56%	53%	47%
Married	Not reported	71%	57%
Employed	81%	87%	92%
Duration of follow-up, years	Annually for 6 years	Mean = 6 years All >3 years after LLD	Mean = 2.8 years
Key findings			
Medical concerns	<ul style="list-style-type: none"> • 66%, >1 LLD-related medical problem • 22%, abdominal pain at year 3 • 28%, pain negatively affected their life • 23%, less physically active after LLD 	<ul style="list-style-type: none"> • 69%, wound numbness • 50%, decreased in abdominal wall tone • 36%, lower back pain • 15%, LLD-related medical problems 	<ul style="list-style-type: none"> • 41%, overall complication rate • 7%, readmission between 1 and 12 months
Psychological/social benefits	<ul style="list-style-type: none"> • 95%, resumed normal activities at 1 year • 90%-95%, would donate again • 81%-88%, "very satisfied" • 82%, reported increased positive outlook/self-worth • 78%, employer was "very supportive" • 55%, positive feelings to share with other donors • <2%, insurance challenges 	<ul style="list-style-type: none"> • >90%, would donate again • All HRQOL measures above US population norms • Low levels of guilt, responsibility in 91 donors whose recipient died • HRQOL similar/better on physical domains, similar/worse on emotional measures • Age >30 years less likely to have poor physical/psychosocial profiles 	<ul style="list-style-type: none"> • 100%, employed donors returned to work after LLD (mean = 10 weeks) • 62%, in stable relationships: 7 donors married; 3 divorced; and 3 widowed
Psychiatric/functional concerns	<ul style="list-style-type: none"> • 21%, different job • 16%, emotional issues at 1 year • 6%-12%, emotional issues at 2-6 years • 12%, out-of-pocket LLD expenses greater than US \$3000 • 8%, major financial hardship 	<ul style="list-style-type: none"> • 58%, LLD-related expenses; 15%, burdensome • 22%, unable to complete prior physical tasks • 11%, life insurance problems • Men had a 6 times higher risk of poor psychological benefit • Longer LOS predicted lower SF-36 MCS score 	<ul style="list-style-type: none"> • 4% of female donors, new or recurrent depression/anxiety

*The percentage given is of the total number of eligible donors.

did not return to their predonation occupation for unspecified reasons. Overall, these data are generally reassuring to transplant teams with the low rate of severe or unexpected medical sequelae after 1 year, and they may help inform administrators and policy makers of the substantial nonmedical costs associated with LLD.

Concerning new insights provided by LaPointe Rudow et al. included the sizable rates of post-LLD emotional distress reported in this otherwise highly

selected and resilient population of healthy donors. Although 70% of the cohort reported no emotional distress during follow-up, 6%-12% of donors consistently reported emotional problems at 2-6 years of follow-up. Unfortunately, the reported emotional symptoms (anxiety, intrusive thoughts, and depression) were not well characterized nor confirmed by a clinician. Furthermore, it is not clear if these emotional issues were related to liver donation, recipient outcomes, or other life circumstances. Nevertheless,

the finding that no donors had received *any* type of counseling or therapy is concerning and highlights the need for more careful assessment and monitoring of LLDs after initial recovery from donation.

The annual number of adult-to-adult LDLTs will likely increase over the next decade given recent changes to deceased organ donor allocation policy and concomitant advances regarding the overall safety profile of partial hepatectomy. In particular, the potential use of laparoscopic surgical techniques could reduce both short-term and longterm donor morbidity, including incisional hernias, as has been seen with living kidney donation. In the interim, there are several ways in which our understanding of the safety and efficacy of LLD can be improved. First, the Organ Procurement and Transplantation Network and other international regulators now mandate reporting of various medical and psychosocial complications among liver donors at the time of hospital discharge and at 6 months, 1 year, and 2 years after donation.^(8,9) However, the content and duration of follow-up in these national data reports may not be detailed enough to detect and respond to crucial nuances in the donors' health and functional status. Expanded prospective medical and radiological assessments are therefore needed to detect occult portal hypertension and vascular/biliary complications as well as changes in donor nutrition and fertility during longterm follow-up. In addition, baseline and follow-up assessments using validated psychometrics are needed to provide higher resolution data on emotional health and adjustment over time. Finally, studies of functional outcomes in LLD lack appropriate comparator groups and would benefit from the inclusion of controls such as LLD candidates evaluated at the same center but excluded on *anatomical* grounds.

Liver transplant programs are continuously challenged to maintain equipoise between living donor safety and the mortality risk to wait-listed patients. The work of LaPointe Rudow et al. provides important new information to help educate potential donors of the longterm risks and benefits of LLD.⁽⁶⁾ As we screen potential donors and communicate detailed risk and benefit information to them, we must now also carefully counsel and guide them regarding their

future longterm health risks and potential financial challenges if they are unable to return to their pre-donation occupation. In addition, this study highlights the need for additional resources and studies to monitor, assess, and treat individual liver donors who develop clinically significant emotional distress after the spotlight of their selfless act of donor heroism fades from our memories.

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