Research Article
Transplantation

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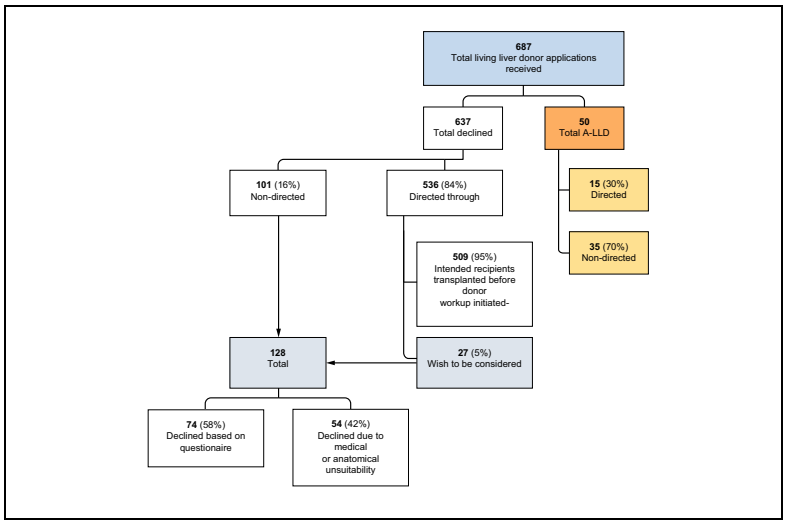
Graphical abstract



Highlights

- Anonymous liver donors can successfully contribute to the donor organ pool.
- Social media can be used to educate communities about this opportunity.
- Anonymous donors are motivated by their values and beliefs and are very satisfied with their experience.

Authors

Nicolas Goldaracena, Judy Jung, Aloysious D. Aravinthan, ..., Gary Levy, Mark Cattral, David Grant

Correspondence

judy.jung@sickkids.ca
(J. Jung)

Lay summary

We report a unique experience with 50 living donors who volunteered to donate to a recipient with whom they had no biological connection or prior relationship (anonymous living donors). This report is the first to discuss motivations, strategies and facilitators that may mitigate physical, social and ethical risk factors in this patient population. With rigorous protocols, anonymous liver donation and recipient outcomes are excellent; with appropriate clinical expertise and system facilitators in place, our experience suggests that other centers may consider the procedure for its significant potential to reduce the gap between transplant organ demand and availability.

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Donor outcomes in anonymous live liver donation

Nicolas Goldaracena[1,2,†], Judy Jung[1,6,*,†], Aloysious D. Aravinthan[1,3,†], Susan E. Abbey[1,4], Sandra Krause[1,4], Cheryl Pritlove[1,5], Joanna Lynch[1,4], Linda Wright[1], Nazia Selzner[1], Jennifer Stunguris[6], Paul Greig[1], Anand Ghanekar[1,6], Ian McGilvray[1], Gonzalo Sapisochin[1], Vicky Lee Ng[6], Gary Levy[1], Mark Cattral[1,6], David Grant[1,6]

[1]*Multi-Organ Transplant Program, University Health Network, Toronto, Canada;* [2]*Division of Transplant Surgery, University of Virginia Health System, Charlottesville, VA, United States;* [3]*NDDC, School of Medicine, University of Nottingham; NIHR Nottingham Biomedical Research Centre, Nottingham University Hospitals NHS Trust and University of Nottingham, Nottingham, UK;* [4]*Centre for Mental Health, University Health Network, Toronto, Canada;* [5]*Applied Health Research Centre, St. Michael's Hospital, Toronto, Canada;* [6]*Transplant and Regenerative Medicine Centre, The Hospital for Sick Children, Toronto, Canada*

See Editorial, pages 864–866

Background & Aims: Death rates on liver transplant waiting lists range from 5%–25%. Herein, we report a unique experience with 50 anonymous individuals who volunteered to address this gap by offering to donate part of their liver to a recipient with whom they had no biological connection or prior relationship, so called anonymous live liver donation (A-LLD).

Methods: Candidates were screened to confirm excellent physical, mental, social, and financial health. Demographics and surgical outcomes were analyzed. Qualitative interviews after donation examined motivation and experiences. Validated self-reported questionnaires assessed personality traits and psychological impact.

Results: A total of 50 A-LLD liver transplants were performed between 2005 and 2017. Most donors had a university education, a middle-class income, and a history of prior altruism. Half were women. Median age was 38.5 years (range 20–59). Thirty-three (70%) learned about this opportunity through public or social media. Saving a life, helping others, generativity, and reciprocity for past generosity were motivators. Social, financial, healthcare, and legal support in Canada were identified as facilitators. A-LLD identified most with the personality traits of agreeableness and conscientiousness. The median hospital stay was 6 days. One donor experienced a Dindo-Clavien Grade 3 complication that completely resolved. One-year recipient survival was 91% in 22 adults and 97% in 28 children. No A-LLD reported regretting their decision.

Conclusions: This is the first and only report of the characteristics, motivations and facilitators of A-LLD in a large cohort. With rigorous protocols, outcomes are excellent. A-LLD has significant potential to reduce the gap between transplant organ demand and availability.

Lay summary: We report a unique experience with 50 living donors who volunteered to donate to a recipient with whom they had no biological connection or prior relationship (anonymous living donors). This report is the first to discuss motivations, strategies and facilitators that may mitigate physical, social and ethical risk factors in this patient population. With rigorous protocols, anonymous liver donation and recipient outcomes are excellent; with appropriate clinical expertise and system facilitators in place, our experience suggests that other centers may consider the procedure for its significant potential to reduce the gap between transplant organ demand and availability.

Introduction

Death rates on liver transplant (LT) waiting lists in the Western world range from 5-25%.[1–4] This is disheartening since most LT recipients now survive for decades with good health and near normal quality of life.[1,5,6] In selected locations, live liver donation (LLD) has been used to mitigate the shortage of deceased donor livers with excellent recipient outcomes. LLD is associated with a 30% morbidity rate and an estimated 0.3% donor mortality risk.[5,7–11,12] Our program and others have confirmed that donors with biological relationships or close emotional bonds with the recipient have few regrets and good outcomes.[8,13]

Early in the development of our LLD program, a donor candidate challenged the requirement for a pre-existing connection between the live donor and recipient. We acknowledged that few centers offer anonymous kidney donation but noted that the latter operation is associated with a much smaller risk. Nonetheless, after a thorough ethical review, we decided to cautiously develop a unique program for anonymous-LLD (A-LLD) and reported favorable preliminary outcomes.[13,14] Herein, we report the characteristics and surgical outcome of the larger A-LLD experience (n = 50 cases) to date. Moreover, we provide rigorous quantitative and qualitative study data from 26/50 A-LLD who agreed to participate in a mixed methods study about their A-LLD experiences. We explored the reasons why people

Keywords: Anonymous living donation; Living liver donation; Live donor liver transplantation.
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* Corresponding author. Address: Multi-Organ Transplant & Medical Specialties, The Hospital for Sick Children, 555 University Ave, Toronto, ON M5G 1X8, Atrium 6709, Canada.
E-mail address: judy.jung@sickkids.ca (J. Jung).
† Authors contributed equally.

volunteer to become LLD despite the significant risks; factors that facilitate this choice; how they feel about this choice afterwards; and the potential of this option to reduce deaths on LT waiting lists.

A-LLD has the potential to alleviate suffering for those waiting for LT. In December 2016, there were 11,140 active patients waiting for a LT in the United States. Also, in that period of time 192,947,800 individuals constituted the US population between the ages of 18 and 65. Therefore, if approximately 1 of 17,000 US citizens in this age range volunteered to donate part of their liver, the entire waitlist could be eliminated. We hope that the good outcomes with A-LLD reported herein will incentivize other programs to consider developing their own protocols for this option.

Patients and methods

Study design

A mixed methods approach was used to characterize the A-LLD experience. This study was approved by University Health Network's Research Ethics Board (REB #:16-5038-AE).

We define A-LLD as a donor with no biological connection and whose identity was unknown to the recipient when starting the assessment. A-LLD were either directed or non-directed. Directed donors donated to a specific individual without the recipient's knowledge. Non-directed donors provide this gift to someone selected by the recipient team.[13,15]

Participants

From January 2005 to December 2017, we performed 2,037 adult and pediatric LTs in Toronto. The study sample includes all patients undergoing A-LLD at the Toronto General Hospital between April 2005 and May 2017. A detailed description of our evaluation and selection process has been reported.[5,16] Briefly, all A-LLD are selected based on compliance with the Health Canada regulations for safe organ and tissue donation and transplantation.[17,18] In addition to a careful medical and surgical work-up, all anonymous donor candidates between ages 16–60 are seen by both social work and psychiatry to assess their mental health, motivation, social independence, willingness to comply with our ethics policies, and support systems. Comprehensive assessments of donor physical and mental health are performed by our team at 1 and 3 months after surgery (or longer if needed) and by the primary care provider annually for 10 years post-donation.

Anonymous, directed donors were allocated to their intended recipients if suitability for the specific recipient was met (*e.g.* blood type, graft volume and anatomy). If they were not suitable, they were offered the opportunity to donate to another recipient. Non-directed A-LLD were given the option to donate to either a child or an adult. We recommended donating the left lateral segment (LLS) as the first option because of the lower risks compared with donation of a full left or right lobe graft (RL),[11,19–22] but respected the donor's autonomy to make an informed decision to donate to an adult if that was their preference. Differences in risks between the different donor procedures were explained in detail to the potential donors in order for them to be able to take an informed decision. When an LLS hepatectomy was not possible due to either anatomical considerations or due to the absence of an available compatible recipient, RL donation was offered. The transplant hepatology team independently selected these recipients based on priority of medical need. Donors, besides knowing if their intended recipients were either a child or an adult, were not provided with any other additional information regarding the recipients.

The first A-LLD operation was performed in April 2005. Shortly thereafter we reported this case and discussed the ethical basis for A-LLD-LT.[14] When evaluating A-LLD candidates, we payed particular attention to: motivation, decision-making, resilience, prior altruism, community service, and social support. Donors were excluded if they demonstrated significant instability in psychiatric/psychosocial functioning or required intensive support to maintain stability. Donors were reminded that Canadian law prohibits profiting in any material way from the donation. Provincial funding provides partial reimbursement of expenses directly incurred through donation.

In 2010, we started asking A-LLD to maintain their anonymity to be congruent with Canadian legal requirements for anonymity with deceased donation.[23] Donors were informed of the immediate transplant outcome but were not informed about the recipient's longer-term condition. We offered to facilitate an exchange of a brief card or letter without identifying information. We did not facilitate meetings between the donor and the recipient although a few pairs have done this through their own initiatives using social media.

Medical, surgical, and socioeconomic data

Medical and surgical data were extracted from our prospectively collected database. Socioeconomic data were extracted from template social work assessments. Mean household income, residency (defined as urban *vs.* rural), and cultural diversity index (defined as high, medium, or low) were approximated from postal code using Postal Code^{OM} Conversion File Plus, Version 6C (Statistics Canada, Ottawa, ON, Canada) and PRIZM5 (Environics Analytics, Toronto, ON, Canada) and compared with normative population data. Where relevant and when data were available, comparisons were made with normative population data or the Ontario National Household Survey Profile 2011 (Statistics Canada Catalogue no. 99-004-XWE, Ottawa, ON, Canada).

Donor quantitative self-report data

Of the 50 identified A-LLD, those who were at minimum 3 months post-donation (41/50) were invited to complete structured questionnaires, and 26 agreed. From the remaining donors (15/41), 12 participants could not be reached and 3 (6%) declined participation due to lack of interest. Post-donation medical and psychosocial follow-up was distinct from this process; while only a portion of donors agreed to participate in the study, all donors completed all of the required medical follow-up post-donation and were subsequently discharged to their primary care provider with a full case summary for ongoing care.

Personality dimensions were explored using the big five inventory, which assesses the degrees of extraversion, agreeableness, conscientiousness, neuroticism and openness.[24] The 4-item relationship questionnaire was used to measure adult attachment styles.[25] It was selected to explore potential associations between the ways in which individuals form relational attachments and the impact this has on the donation decision given some evidence that secure attachment increases compassion and altruism.[24] The post-traumatic growth inventory (PTGI)[26] was administered to examine positive changes donors might have experienced. The PTGI was administered with a preamble explaining that donors have described LLD as a positive but unexpectedly difficult experience in order to clarify

the original instructions in which the event in question is referred to as a "crisis/disaster."

Donor qualitative data

Everyone who completed the structured questionnaires participated in semi-structured qualitative interviews. Transcripts were independently coded during data collection to identify emerging themes, often by identifying unique terms used by the participants themselves (*e.g.* "Life-changing").[27] During the interview process, the investigators met as a group to reach consensus on key codes and themes directly related to the project objectives and recurring across multiple interviews.[28] To confirm importance and identify associations, transcripts were critically re-analyzed using the constant comparison method.[28]

Statistical analysis

Data are shown as median (range) or number (percentage) unless otherwise stated. Data were analyzed for significance using SPSS 22 statistical package (IBM, Chicago, USA). A p value of <0.05 was considered significant.

Results

A-LLD characteristics

In the study period, 743 LLD were performed at our institution. Fifty (6.7%) were performed anonymously. The annual rates of anonymous donation have been stable for the past 5 years. Self-reported questionnaires were received from 26 (63%) patients out of the 41 A-LLD who were more than 3 months post-donation. All respondents also volunteered to participate in a qualitative interview.

Donor characteristics are summarized in Table 1. Fifteen (30%) A-LLD were directed, having learned of the specific recipient's need through media appeals and community news. Over half of donations (n = 28, 56%) went to a pediatric recipient while the remainder (n = 22, 44%) went to adult recipients.

Twenty-six (52%) were women and 24 (48%) men. Median age was 38.5 years (range 20–59). Most were Caucasian (n = 47, 94%). Many were married or in a common-law relationship (54%) and many had children (40%). Fig. 1 depicts their socioeconomic status compared with Ontario normative populations.

How donors learned about living liver donation as an option

More than two-thirds of donors (n = 33, 70%) came forward after learning about the growing need for organ donation through media appeals on behalf of patients on the transplant waiting list in local, national or social media. Only 8 donors knew somebody who has been a solid organ transplant recipient. Twenty-seven patients found out through the media about the organ shortage, a patient in need of a LT or stories about previous live donors; 6 patients found out through their community involvement (*e.g.* place of work, church/temple, *etc.*) about somebody in need of a LT; 6 donors knew somebody in need of a LT but upon finding they would not be a suitable match, opted for non-directed donation; 5 donors directed to someone with whom they had an existing relationship but wished to remain anonymous; 3 had a family member who benefited from LT and wanted to reciprocate; 1 was previously a bone marrow donor and felt that he wanted to do more; 1 had a relative die while waiting for a LT; 1 donor was a healthcare professional who had witnessed many patients affected by the need for transplant.

Table 1. Donor characteristics.

Donor characteristics	N = 50
Median age at donation (years)	38.5 (20–59)
Female	26 (52%)
Median BMI at donation	24 (18–30)
Previous surgery	25 (50%)
Previous altruistic act	34 (68%)
Other solid organ donation	4 (8%)
Know a transplant recipient of a solid organ	8 (16%)
Median evaluation time (days)	94 (18–681)
Directed anonymous donation	15 (30%)
Non-directed anonymous donation	35 (70%)

BMI, body mass index.

History of altruism

The majority of donors (n = 34, 68%) had a history of altruistic acts prior to liver donation. This included volunteer work in their local community and/or with international charity organizations (n = 23, 46%), regular or *ad hoc* blood donation (n = 20, 40%), and solid organ donation (n = 3, 6%). Two of the donors had a prior history of anonymous living kidney donation. One donor underwent bone marrow donation prior to liver donation. Median evaluation time for all donors was 94 (18–681) days.

Response to public/media appeals

The flow of donor applications and their outcomes during the study interval is shown in Fig. 2. During the study interval, in addition to the completed donations described, there were another 637 anonymous donor candidate applications received. From them, 536 (84%) candidates submitted as directed donors in response to media appeals of various scales or advocacy on behalf of recipients by family members. The remaining 101 (16%) submitted as non-directed donors. Of the directed donor group, 509 (95%) donor files were closed after the intended recipient received a transplant and before the formal donor work-up was initiated. Upon notification of their file closure, 27 (5%) candidates indicated they wished to be considered as non-directed donors in response to a missed opportunity to donate to the individual for whom they responded initially. Of the combined non-directed group of 128 donors, 74 (58%) were rejected after reviewing the screening questionnaire, most commonly due to a body mass index higher than the upper maximum of 35 kg/m^2 or health-related contraindications. The remaining 54 (42%) non-directed donors were rejected at various stages after starting a work-up due to medical or anatomical unsuitability.

Donor surgical outcomes

Donor surgical outcomes are summarized in Table 2. Thirteen donors (26%) experienced a complication (Table 3). Only 1 major complication (Dindo-Clavien ≥3b) occurred. This donor required re-operation to evacuate a hematoma.

Median hospital stay was 6 (4–11) days. Median time to return to work was 12 weeks (3–24 weeks). One donor with a deep vein thrombosis has persistent leg edema that limits vigorous physical activity.

Personality traits

When compared with the general population. A-LLDs had higher scores on the big five inventory[22] in agreeableness (mean = 4.24, SE = 0.11, p <0.0001) and conscientiousness

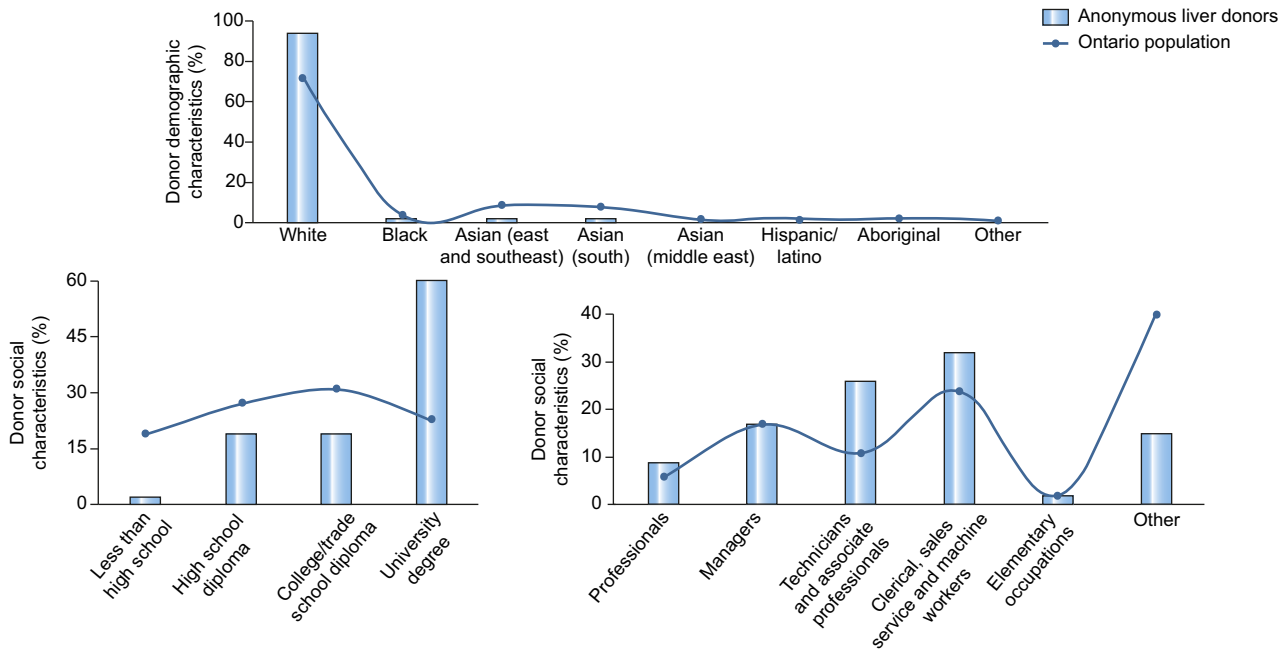

Fig. 1. Donor sociodemographic characteristics.

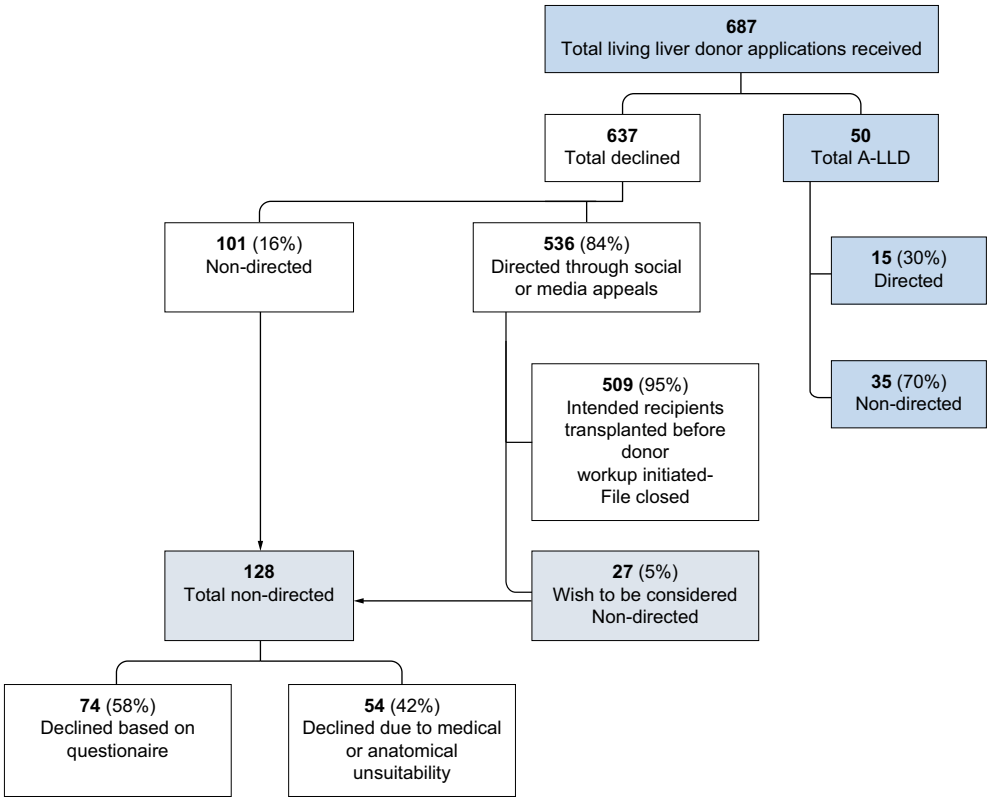

Fig. 2. Flow of donor applications.

(mean = 4.28, SE = 0.09, p <0.0001); and lower scores on neuroticism (mean = 2.27, SE = 0.15, p <0.0001).

Attachment style

Close to half of the respondents (13 donors, 50%) identified with secure attachment (Table 4). A third of respondents (8 donors) identified with a dismissing attachment style. Four (15%) respondents reported having a fearful attachment style.

Perspectives on anonymity

Forty-four donors (88%) maintained anonymity. The remaining 6 donors (12%) met their recipients or their families, personally

Table 2. Donor surgical outcomes.

Donor surgical outcomes	N = 50
Donation to a pediatric recipient	28 (56%)
Right lobe donation	21 (42%)
Left lobe donation	5 (10%)
Left lateral segment donation	24 (48%)
Intraoperative blood transfusion	1 (2%)
Postoperative blood transfusion	1 (2%)
Re-operation	1 (2%)
Postoperative Complication	13 (26%)
Postoperative complications within 30 days	10 (20%)
Dindo-Clavien ≥3b	1 (2%)
Long-term complication	3 (6%)
Length of Hospital Stay (days)	6 (4–11)
Hospital re-admission within 30 days	1 (2%)

or in an indirect manner through electronic media. One of the donors experienced mild distress related to the recipient family pursuing more contact than they were comfortable with, which resolved with counseling. Three donors who disclosed to their recipient were interviewed. During those interviews, donors noted that it was gratifying to see the result of their donation and reported that they do not regret the disclosure.

Psychological growth subsequent to A-LLD

Fig. 3 summarizes self-reported post-traumatic growth. Significant growth was reported in the "relating to others" subscale (mean = 10.33, SD = 7.2); of these, "I more clearly see that I can count on people in times of trouble," and "I learned a great deal about how wonderful people are," were most strongly identified as areas of change with endorsement at a moderate score of ≥3 by 41% and 44% of respondents respectively.

The themes arising from the qualitative interviews

Major themes that emerged during the qualitative interviews are summarized in Table 5. Data saturation was achieved when using grounded theory for this analysis. Information from the final interviews did not yield new concepts and the relationships between the categories were clear. The concept of a good deed, a random act of kindness that would contribute to helping someone in need without the expectation of reciprocity or repayment, was identified as a core motivator. As healthy individuals, the moral obligation to help someone in need was frequently mentioned as a major factor and a moral imperative in decision-making to donate. Many reported an emotional reaction to an appeal from a potential recipient

Table 3. Donor surgical complications.

N	Complication	Treatment	Comments
1	*Clostridium difficile* colitis	Antibiotics	
2	DVT and PE	Anticoagulation	Long-term leg edema
3	Urinary tract infection	Antibiotics	
4	Incisional hernia	Surgical repair	
5	Intra-abdominal collection	Percutaneous drainage	
6	Incisional hernia	Surgical repair	
7	Subphrenic collection	Self-resolved without drainage	
8	Pleural effusion	Drainage	
9	Fever	Self-resolved	
10	Brachial plexus injury	Physiotherapy	Ad-integrum recovery
11	Intra-abdominal hematoma	Surgical evacuation	
12	Incisional hernia	Surgical repair	
13	Postoperative ileus	Fasting and IV fluids	

DVT, deep vein thrombosis; PE, pulmonary embolism.

Table 4. The relationship questionnaire.

Attachment style	Description
Secure	It is easy for me to become emotionally close to others. I am comfortable depending on them and having them depend on me. I don't worry about being alone or having others not accept me.
Dismissing	I am comfortable without close emotional relationships. It is very important to me to feel independent and self-sufficient, and I prefer not to depend on others or have others depend on me.
Preoccupied	I want to be completely emotionally intimate with others, but I often find that others are reluctant to get as close as I would like. I am uncomfortable being without close relationships, but I sometimes worry that others don't value me as much as I value them.
Fearful	I am uncomfortable getting close to others. I want emotionally close relationships, but I find it difficult to trust others completely, or to depend on them. I worry that I will be hurt if I allow myself to become too close to others.

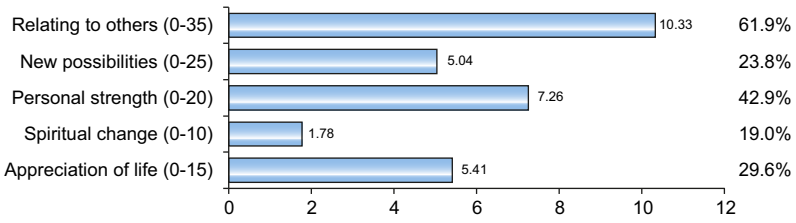

Fig. 3. Mean scores of post-traumatic growth inventory subscales and percentage of donors endorsing significant growth (≥3).

Table 5. Major qualitative themes associated with anonymous liver donation.

Theme	Quote
Anonymity	"I think [speaking about my donation] diminishes the real purpose of what I've done, because then it feels like I'm there because I'm looking for the accolades and that's, I really don't feel that's why I did this."
Awareness	"I didn't even know you could donate a liver. I had no idea any of this was possible. And I read that post [on Facebook] and I thought 'Oh my God, ok, I'm the same blood type, so you need to help.'" "I just think that people don't think about it and the only time you do talk about organ donation or the only time it's raised in the public consciousness is like the occasional news story."
Barriers and facilitators to donation	"Frankly, if I didn't have health insurance and if I was in a worse financial situation, I might not have been able to afford [to donate]." "So there's the employer support, the insurance support and obviously, the biggest support is family. Your family has to be fully supportive of you."
Disclosure	"...when you start telling people you're doing this, it's automatically taken the wrong way by a lot of people. People are generally really suspicious, so they think you're doing it for money, which is unfortunate, because I had to raise money. So, people would get the wrong impression that way." "I'm uncomfortable, to some degree, talking about it with other people, because I don't want people to get the impression that I did this for myself. Like, for some sort of boastful or, 'Hey, look at me and look how great I...' Like that was never the intent."
Perceived gaps in care	"I think from a doctor's perspective, they checked in to say, 'Your partner knows?' 'Yeah,' 'Okay, everything's fine.' And everything was fine, but they never asked to see him. They never asked to talk to him..." "...like going from apprehension when you're waiting to find out, to elation [when you are accepted as a donor], to like somebody gut-shot you or something [when you're told you can't donate]...I was devastated."
Impact of donation	"I'm less fearful of what I can accomplish and less fearful of new experiences, and I enjoy busting through my comfort zone now. I really enjoy it, because the best experiences in my life came from doing that." "It was a good experience with my family. We're all really close anyways, but it was something that we did together. I don't think I would have been able to do it myself ...I needed people to help me during the first few days recovering so it was something that we did together. And when you go through something like that it makes you closer." "It's the most important thing that I've done with my life so far. It's kind of nice to not just know that I did it, but to know that you can do things that seem a bit ridiculous or farfetched. It was really important." "The entire experience has been kind of really falling in love with my body and how it works and appreciating all those amazing things that it can do."
Reasons to donate	"I guess it's a part of me that I'll be leaving in this world. I couldn't have children. And so, people say, 'Well, I want to have children so that when I go they know I've been here.' Well, they'll always know I've been here." "Once I had personally become connected to the need, if there was any way possible that I could contribute, I was ready to do that." "And the reason I was looking [at anonymous donation] was because I have always enjoyed random acts of kindness...there was no way to pay it back and I liked putting that out into the world, because so many times, there's ulterior motives." "I have not led a perfect life. Nobody has. I haven't been particularly awful. I haven't been particularly fabulous. But, that if nothing else, this experience has given me the opportunity to point to one thing in my life that nobody could argue was wrong." "There really wasn't a decision to donate. I didn't know that you could save somebody else's life while you were still alive. I thought it was only post-mortem. So there was no decision. It was like, oh, you can do that. Then I'm in."
Perceptions of living liver donation	"I just imagine the body as like a vehicle, right? Some people are dealt a lemon and if I have a spare part that can be helpful for someone else's lemon, then I'm going to share it. That's how I was thinking of it, this is my vehicle and we have this technology for a reason, so why not?"
Relationships	"I am embraced by the organ transplant community and they're incredible. I've met so many people that are phenomenal people and it just keeps going." "My dad and I definitely have this, we were really well bonded, but this incredible journey together from him, like literally being by my bedside when I was in the hospital every time, all my testing, everything, he was right there with me."
The recipient	"People said 'Oh, it was a child, oh, you must feel so great.' And I said, 'Well, of course, but I would feel the same if it was an adult, because they deserve it just as much as anyone else.' I didn't want to be the person to make that decision. I wanted it to be a decision based on what was the right fit. I didn't want to be the one to narrow it down and create limitations." "I don't know anything about them. So I don't have that emotional attachment." "I wonder how they are. I wonder if they're getting that second lease on life and if they're taking advantage of it and if they're pushing their own boundaries or, you know, what they're experiencing."
The scar	"It's almost like all the trophies on my wall. It's like a trophy for me. It was... it's the marker of my experience and something I have been able to be a part of and achieve in my own life, so it's essentially like a trophy." "Even when I have a rough day, I can look back at my scar and think, you know what, it really doesn't matter, because you have saved somebody's life." "Every time I look at this scar, it's a reminder of how lucky I am to be fit and healthy."

in the news or social media, in some cases making associations with their personal histories or relationships. Most believed that anonymity helped to preserve the value of doing a good deed.

Finances and practical arrangements for work or family matters were reported as challenging factors in the donation process. Universal healthcare and generous employment benefits were facilitators. Most donors reported increased confidence in their ability to cope with problems and connect with others as a result of overcoming these challenges.

Validation in the health and strength of their own bodies were frequently reported in statements about impact post-donation. Donors were grateful that they were sufficiently fit to donate and reported feeling empowered by the process of recovering their health. No A-LLD expressed regret.

Transplant outcomes

Table S1 summarizes the recipients' characteristics (*e.g.* age, gender). The main indication for LT in the pediatric population was biliary atresia (39%), followed by a metabolic disease

(32%). In the adult population, the main indication for LT included primary sclerosing cholangitis (23%), hepatitis C (18%), and alcoholic cirrhosis (18%).

Graft and patient survival for the pediatric population at 1-, 3- and 5-years was of 97%. Graft and patient survival for the adult population at 1-, 3- and 5-years was 91%/86%/81% and 91%/86%/86%, respectively.

Discussion

We performed our first A-LLD in 2005.[14] Motivated by improvement in a friend's quality of life after solid organ transplantation, a 45-year-old man stepped forward offering to donate the LLS of his liver to any suitable child. He challenged our initial practice of restricting donation to those with a direct biological or strong emotional connection with the recipient by asserting 1) he was entitled to make well-informed autonomous decisions about undertaking voluntary health risks; and 2) we should seize this opportunity because saving lives is the most important human and healthcare system value.[13]

Why do people volunteer to donate part of their liver to a stranger? The qualitative interviews reveal a perceived moral duty to step forward given good health and the great need. Public appeals are credited with raising awareness of the opportunity to save a life by these means. Some personalize the experience of the unknown recipient, stating that they hope that someone else would do this for them should they ever become ill with liver failure. Giving back in acknowledgement of a privileged life is another prevalent motivation. Some identify a desire for reciprocity recalling a specific event or time in their life when others helped them. Finally, many note that anonymous donation is a more accurate term than altruistic donation since the donor also benefits from a thorough work-up and the satisfaction of helping others in an extraordinary way.

A-LLD were predominantly Caucasian, well-educated, financially secure, socially-supported urban residents from many different walks of life. Their stable personal circumstances and gainful employment facilitated decisions to donate anonymously. Thirty-five (70%) had a history of prior altruistic acts before becoming an LLD. We elected to move forward with the 30% who did not have a history of prior altruistic acts based on their clinical presentation and our careful social work and psychiatry evaluations.

Whether it is reasonable for a single individual to undergo 2 living donations raised safety and ethical questions for the program; several cases were approved following a detailed assessment in compliance with standards under the Canadian Standards Association Cells, Tissues and Organs for Transplantation: General Requirements.[17,18] Four donors either were or subsequently became live kidney donors. An additional 3 donors have completed kidney donation assessments and are currently awaiting recipient matching, while one has anonymously donated bone marrow.

Seventy percent of the A-LLD became aware of the opportunity to donate through social and public media appeals. This group fell into 3 broad categories: a) those who donated directly to the intended recipient, b) those who responded to an appeal for an individual but donated to someone else after a missed opportunity, and c) those who stepped forward without a specific recipient in mind after learning of LLD through media or their community. Information about the liver's ability to regenerate itself to restore normal function and the lack of alternative treatment options for liver failure were frequently cited as an important reason to opt for liver donation instead of kidney donation. Concerns about fairness, privacy and risk of donor and recipient exploitation have been raised with respect to public solicitation of living organ donation. We have tried to address these issues by strictly adhering to transparent medical, legal, and ethical policies guiding directed live donation.[31]

Those who knew the identity of their recipient reported a heightened level of distress during and after donation about protecting their identity. This group focused on the fact that disclosure of their identity may bring unwanted attention and create unrealistic expectations of their character. Moreover, donors in this group worried about their own expectations of the recipient, expressing that knowing too much about the recipient or establishing a relationship with them might be an unfulfilling experience or change their impression of the experience. This group reported that they felt protected by the anonymity policy with which they were prepared during the assessment process.

Bioethics, clinicians, regulatory groups and other content experts were consulted in formulating our policies around anonymity and disclosure. Given reported concerns from donors and the potential detrimental impact to both donors and recipients in the case of a negative outcome, the program completely anonymizes the process of A-LLD and does not engage in donor-recipient disclosure.

Structured questionnaires revealed personality traits that facilitated calculated risk-taking to help others. Donors identified themselves as agreeable, conscientious, orderly and responsible with low neuroticism. These traits are consistent with literature showing that securely attached individuals find comfort in reciprocity and close relationships with others, exhibit greater compassion, have a greater willingness to help others in distress or need, and have fewer egoistic motives.[24,29] While a fearful-avoidant attachment style is inversely related to the helping behavior, engagement may be associated with a more egoistic motive (*e.g.* a sense of belonging, the satisfaction of a good deed). While such individuals also tend to experience challenges with seeking assistance and depending on others, individuals in this cohort nevertheless had a positive outcome with appropriate screening and support. The present analysis suggests that these collective personality traits are also associated with a low risk of experiencing regret or poor quality of life following LLD.[30]

Donor and recipient physical outcomes in the anonymous cohort were similar to the outcomes reported for directed donation to individuals with whom the donor has a biological or close emotional relationship.[5,9] Overall and major complication rates were 26% and 2%, respectively. A-LLD acknowledged that this experience was not easy but believed that they also benefited by gaining insight into their personal strength and the value of key relationships.

This study has limitations and strengths. Biases or confounding factors may have been introduced by mixing retrospective and contemporaneous data collection. There is an opportunity to compare non-A-LLDs as a control group, an analysis which is currently underway. As with all surveys, we do not know the views of the non-respondents and this report may exclude understanding of poorer outcomes or experiences. However, the response rate of 51% is consistent with other qualitative research studies and data saturation was achieved when using grounded theory for the qualitative analysis. Our consistent

protocol-driven processes for donor evaluation, donor acceptance, surgery, and post-operative follow-up are other strengths.

We have previously reported our perspectives on the ethical foundation for A-LLD, proposing that decisions about candidates should be based on the ethical principles of autonomy, beneficence, non-maleficence, and informed consent.[14] Programs providing A-LLD face many challenging questions with no clear answers. For example, is it ethical to expose good Samaritans to surgical morbidity and even a risk of dying when there are options to expand the use of deceased donor organs by treating with machine perfusion? Is it reasonable to let someone decide if they are willing to accept a slightly higher surgical mortality risk to donate a larger portion of their liver to an adult rather than a smaller portion of their liver to a child? Is it ethical to offer donation of a liver when someone has already donated a kidney and has slightly reduced renal function? Currently, Canadian regulations on living organ and tissue donor suitability assessment are limited to specific exclusionary criteria pertaining to behavioral risks of infection (Table S2). These standards are important for minimizing potential health risks to the recipient. Regulations currently provide guidance on a physical exam of the living donor in broad strokes, but the outcome remains dependent on the expertise, decision and confidence of the medical providers. However, the decision of suitability beyond infection risk must take into consideration the nuances of donor history, psychosocial characteristics and a thorough review of the clinical assessment in its entirety. To ensure sound ethical decision-making and mitigation of safety risks as much as possible, our program has developed a donor-centric, expertise-based multidisciplinary approach. For example, when considering suitability of sequential liver and kidney donors, we consult specialists from both kidney and LT teams, as well as independent medical consultants. A collaborative decision is made that complies with national regulations as well as expert opinion on overall clinical risk. Teams offering A-LLD are therefore, moral agents in this process and must carefully weigh the individual benefits and risks for each candidate. National regulatory bodies recognize that in order to optimize national programs and standards, a more coordinated model towards clinical governance is needed and programs are recommended to collaborate by standardizing operating procedures that consider both recipient risks as well as donor safety. We continue to use our experiences to contribute to this effort.

When discussing this experience, we were frequently asked: *Can this experience be replicated elsewhere?* It is up to others to answer this question, but we acknowledge many advantages that facilitate caring for these courageous volunteers. First, Canada's publicly funded universal healthcare system eliminates the financial burdens that might otherwise be associated with donor assessment, surgery, and long-term care. Second, our legal system supports LLD through employee-friendly workplace regulations and reasonably generous social supports for those who become ill or disabled.[30] Third, the Ontario government has reduced financial barriers by reimbursing most of the donor's direct costs of LLD, including travel and accommodation expenses, a program for which all Ontario donors universally quality (PRELOD, Trillium Gift of Life). Fourth, Canadian culture supports live organ donation by valuing civic freedoms, compliance with laws, contributing to community, fairness, and a polite comfort with individual choice.[31,32] Reflecting these values and prevailing public views, Canadian media reports about altruistic donation have been generally positive. Lastly, our assessment process is focused on facilitating the generous intent of donor candidates without compromising safety.

A-LLD not only saves the life of the transplanted recipient, it also reduces the demand on the deceased donor waiting list. A-LLD is particularly valuable for pediatric recipients because it provides healthy, high quality grafts and reduces the risk of recipients deteriorating on the waiting list. Access to this option helped to reduce our pediatric wait list by 38% between the years 2014–2017 when A-LLD rates temporarily spiked due to multiple high-profile media solicitations.

A-LLD comprises an overall small percentage of our LT activity. During the study period, 2.45% (50/2037) of our overall LT activity and 6.73% (50/743) of our LLD activity was done through A-LLD. However, this option is a small but important part of a multifaceted effort at our center to reduce deaths on our LT waiting list, complimenting other measures such as transplanting extended criteria deceased donor grafts with and without machine perfusion storage.

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Conflict of interest

The authors declare no conflicts of interest that pertain to this work.

Please refer to the accompanying ICMJE disclosure forms for further details.

Authors' contributions

Nicolas Goldaracena: conception and design of the study; generation, collection, assembly, analysis and interpretation of data; Statistical analysis; drafting of the manuscript; critical revision of the manuscript for important intellectual content; approval of the final version of the manuscript. Judy Jung: conception and design of the study; generation, collection, assembly, analysis and interpretation of data; Statistical analysis; drafting of the manuscript; critical revision of the manuscript for important intellectual content; approval of the final version of the manuscript. Aloysious Aravinthan: generation, collection and assembly of data; analysis and interpretation of data; Statistical analysis; drafting of the manuscript; critical revision of the manuscript for important intellectual content; approval of the final version of the manuscript. Susan Abbey: generation of data; analysis and interpretation of data; critical revision of the manuscript for important intellectual content; approval of the final version of the manuscript. Sandra Krause: generation, collection and assembly of data; critical revision of the manuscript for important intellectual content; approval of the final version of the manuscript. Cheryl Pritlove: generation, collection, assembly, analysis and interpretation of data critical revision of the manuscript for important intellectual content; approval of the final version of the manuscript. Joanna Lynch: generation, collection and assembly of data; critical revision of the manuscript for important intellectual content; approval of the final version of the manuscript. Linda Wright: generation, collection and assembly of data; critical revision of the manuscript for important intellectual content; approval of the final

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Supplementary data

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