Directed and Non-Directed Anonymous Living Liver Donors

Authors: Whitney E. Jackson, MD and Dianne LaPointe Rudow, ANP-BC, DNP, CCTC
Editors: Vineeta Kumar, MD and Andrea DiMartini, MD

ISSUE

How are directed and non-directed anonymous living liver donors evaluated?

DATA

Anonymous organ donation began in 1999 with a living donor kidney transplant(1) and has now expanded to other solid organs, most notably, liver transplantation. Anonymous organ donors may be directed or non-directed. Directed anonymous living liver donors present for donation to an intended recipient, often responding to social media or another form of solicitation. Non-directed anonymous living donors present for donation to anyone in need, without an intended recipient in mind. According to the US Scientific Registry of Transplant Recipients (SRTR), liver transplants from non-directed anonymous living liver donors have been increasing with 105 reported between 2000 and 2019; remarkably with 39 in 2019 alone.(2)

Transplant teams have an ethical responsibility to ensure a donor’s protection from psychological harm from donation.(3) This responsibility historically has led to acceptance of biological and emotionally related donors, but some hesitancy to support unrelated donors. Yet, the increasing numbers of anonymous donors suggests a growing acceptance of a spectrum of emotional relationships between donor and recipient when carefully evaluated. Some may argue that the non-directed anonymous donor may be the only donor that is truly autonomous and free from potential coercion.(4)

While maintenance of anonymity is recommended by the United Network for Organ Sharing (UNOS) to free the donor from potential pressure or coercion(5), anonymity may not be possible in directed donation as the donor-recipient relationship may evolve during the evaluation process. Most centers will require a non-directed donor remain anonymous until a period of time has passed after donation. Transplant centers must develop a policy for anonymity of non-directed living donors.
Evaluation

All potential living donors undergo comprehensive medical and surgical evaluation as well as counseling with an independent living donor advocate. Concerns raised about directed and non-directed anonymous donors specifically have included: donor psychological status, motivation, knowledge and expectations of donation, and the potential for undue pressure whether that be emotional or financial. For example, an anonymous donor may enter the evaluation process with much less knowledge about transplantation than a family member of a recipient who has been a caregiver through this chronic illness. That lack of knowledge may translate to vulnerability to an emotional appeal over the internet without an understanding of the potential treatment options for that potential recipient. Additional potential “red flags” requiring more investigation are potential donors with a history of psychiatric disorder, limited financial capacity or lack of health insurance, limited ability to understand donor risk and recipient benefits, and motives that reflect a desire for recognition. Hence, these donors undergo thorough psychosocial evaluation.

Washington University in St. Louis described their protocol for evaluating non-directed liver and kidney donors which includes two self-administered psychological instruments, a psychiatric interview to assess motivation and DSM criteria pathology, and family interview for corroboration and to assess support. The University of Toronto requires a formal psychiatric assessment with attention to the motivation of the donor and assessment of their understanding of the donation process. Additional supportive criteria include a history of altruistic acts, rationale for donation, lack of psychiatric or psychosocial issues, strong social support, and willingness to maintain confidentiality with no expectation of secondary benefit such as media attention or illegal compensation.

It is generally accepted that live liver donation should only be performed if the risk to the donor is justified by an expectation of an acceptable outcome in the recipient. This has been modeled through the concept of the double equipoise, balancing donor risk and recipient benefit. UNOS guidelines state that living non-directed donation is justified provided a strict standard of informed consent is followed, the donor undergoes appropriate evaluation, and organs are allocated in an equitable manner. Transplant centers must develop a policy for allocation of non-directed living donors stating how the organ will be placed and rationale for selection.

Outcomes

The University of Toronto recently reviewed donor outcomes from 50 anonymous living liver donors, which included both directed and non-directed donors. Their cohort was well educated and had a history of altruism. Social and financial support in Canada was identified as facilitators. Donor outcomes were excellent with one Clavien grade 3 complication. Donors reported increased feelings of self-worth and no donor regretted their decision to donate. Additionally, a North American multicenter collaboration between University of Southern California, the University of Colorado and the University of Alberta was recently able to show that non-directed living liver donors maintain excellent health-related quality of life after donation. Hence, at this time based on small cohorts, overall outcomes for carefully selected non-directed living liver donors at
high volume centers are similar to or better than that of emotionally or biologically related donors.(13,14).

RECOMMENDATIONS

1. Anonymous living liver donors must undergo the same process of evaluation as other living donors.
2. Motivation for donation must be explored carefully by a psychosocial professional with careful attention paid to red flags.
3. Psychological outcomes after non-directed donation are promising but warrant additional longer term follow up to ensure protection of this population.
4. Centers must develop a protocol for allocation of the non-directed anonymous living liver donor based on current allocation guidelines and ethical principles.

REFERENCES


For more information on Living Liver Donation, please refer to our website, generously supported by Novartis.