Candidate Engagement: Strategies to Help Liver Transplant Candidates Pursue Living Donation

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I Have No Disclosures
Objectives

• List why the issues with candidate engagement may be different for the Liver transplant candidate
• Identify practices that have been successful in helping liver transplant candidates pursue LDLT
• Review results from the Living Donor Liver Transplant Consensus Conference and how it can help programs increase LDLT
Are the issues with candidate engagement in the liver transplant candidate different from the kidney candidate?
Best Practices in LDKT

Consensus Conference recommendations 2015

- Centers should develop a philosophical approach that LDKT is the best option for all eligible transplant candidates
- LDKT education of patients with stages of CKD should be repeated and occur at multiple points
  - first learning that a patient’s kidneys are failing (at diagnosis)
  - starting dialysis or preparing for a preemptive transplant (at treatment initiation)
  - During transplant evaluation process
  - While waiting for a deceased donor transplant
  - While seeking and finding a living donor and receiving a living donor transplant
- Standardize LDKT content and processes for living donation across centers
  - Single point of access — centralized
  - Comprehensive risk and benefit information about LDKT
  - Share stories about real life LDKT and LKD experiences
- AST Live Donor Tool Kit: https://www.livedonortoolkit.com/
- Living donor Storytelling Project: https://explorelivingdonation.org/
Best Practice for Engagement in LDLT may be Different than LDKT

**Recommendations:**
- Centers should develop a philosophical approach that LD is the best option for all eligible transplant candidates.
- LD education of patients with stages of CKD should be repeated and occur at multiple points.
- Standardize LD content and processes across centers.
- AST Live Donor Tool Kit: [https://www.livedonortoolkit.com/](https://www.livedonortoolkit.com/)

**Issues Unique to Liver Donation**
- Not all centers believe LDLT is the best option for all candidates.
- Makes sense that liver patients should have education repeated at multiple points in time during disease process. But patients are followed by community GI practitioners: structure and beliefs about LDLT vary.
- Standardized LDLT content and processes across centers is not possible yet as practice varies greatly.
- Provider and Patient tool kits have been developed AST Live Donor Tool Kit: [https://www.livedonortoolkit.com](https://www.livedonortoolkit.com/)
- Consensus Conference papers in press.
Current Status of Living Donor Liver Transplant status in US (LD 5-6%)
The American Society of Transplantation hosted a virtual consensus conference (October 18-19, 2021), bringing together experts in the field with the aim of identifying barriers to broader implementation of LDLT. Recommendations were made regarding strategies to address barriers.

Question remains: How can you expand LDLT more broadly?
LDLT: A Multi Center/Society Collaboration Towards Growth and Consensus

- Current Status of LDLT in the United States & Abroad
- **Selection and Engagement of the Liver Transplant Candidate for LDLT**
- Grey Zone Donors
- Strategies to Expand Donor/Recipient Matching
- Technical Advances in LDLT and Surgical Training
- Specific Barriers and Considerations in Pediatric LDLT
- Ethics, Policy & Expanding LDLT
Table 1: Candidate Selection and Engagement (n=46, 90.2% response rate)

<table>
<thead>
<tr>
<th>#</th>
<th>Priority Importance of Barrier</th>
<th>Strategy(ies)</th>
<th>Consensus Responses</th>
<th>Mean (SD); Median (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Gaps in the knowledge on benefits, risks and timing of LDLT and the risks/benefits to the living liver donor among transplant physicians and referring providers</td>
<td>Importance:</td>
<td>8.39 (0.93); 9 (8, 9)</td>
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<td>#2</td>
<td>Lack of uniform consideration of the benefit of LDLT in select patients with low MELD-Na among transplant and referring providers. For example, many transplant providers are unaware that low MELD-Na (&lt;15) patients with sarcopenia, frailty, decompensating events, infections, or women benefit from LDLT, compared to waiting for rise in MELD-Na or LDLT.</td>
<td>Importance:</td>
<td>8.19 (0.87); 8 (8, 9)</td>
<td></td>
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<td>#3</td>
<td>LDLT in the United States and some other regions is not always considered a first choice for many pediatric patients eligible for liver transplant</td>
<td>Importance:</td>
<td>8.02 (1.05); 8 (7, 9)</td>
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<td>#4</td>
<td>Limited institutional commitment to enable the liver transplant program to develop optimal living donor liver transplantation practices to benefit a large proportion of candidates on the waiting list.</td>
<td>Importance:</td>
<td>8.02 (1.03); 8 (8, 9)</td>
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<td>#5</td>
<td>In critically ill patients, centers need sufficient surgical/medical experience to provide optimal pre- and post-surgical management.</td>
<td>Importance:</td>
<td>7.79 (1.55); 8 (7, 9)</td>
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<td>#6</td>
<td>Accurately knowing which patients with extended HCC criteria (without vascular invasion and extrahepatic mets), based on disease burden and tumor biology, will benefit from a LDLT from a survival perspective.</td>
<td>Importance:</td>
<td>7.54 (1.19); 8 (7, 8)**</td>
<td></td>
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<tr>
<td>#7</td>
<td>Pediatric transplant clinicians lack agreement on the benefits of pediatric LDLT</td>
<td>Importance:</td>
<td>7.53 (1.52); 8 (6, 9)</td>
<td></td>
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<td>#8</td>
<td>Ethical concerns regarding donors’ risks and recipients’ benefit limits the possibility of LDLT in patients with relative poor/unknown prognosis (non-resectable colorectal liver metastases and intrahepatic cholangiocarcinoma)</td>
<td>Importance:</td>
<td>7.52 (1.53); 8 (7, 9)</td>
<td></td>
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<tr>
<td>#9</td>
<td>There is a low level of acceptance of LDLT among candidates on the liver transplant waiting list.</td>
<td>Importance:</td>
<td>7.40 (1.64); 8 (7, 9)</td>
<td></td>
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<td>#10</td>
<td>Lack of data on LDLT for non-resectable colorectal liver metastases and intrahepatic cholangiocarcinoma outcomes to justify exposure of a healthy donor to a major surgery</td>
<td>Importance:</td>
<td>7.09 (1.53); 7 (6, 8.5)**</td>
<td></td>
</tr>
</tbody>
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Lack of Awareness, Acceptance, and Engagement of LDLT

• Several of the identified barriers focused on domains related to a culture of reluctance or even resistance towards LDLT across providers (referring MDs and transplant providers) as well as candidates.

• There was agreement that LDLT has the potential to be beneficial for the recipient when balanced against the risk of the donor.

• Strategies to improve acceptance/education/engagement:
  • Develop education for referring and transplant providers on risks and benefits for the candidates and living donors including appropriate timing of referral and candidate selection.
  • Broader clinician engagement and awareness of the benefits of LDLT to the transplant candidate is paramount and needs to occur before patients can be appropriately engaged.
  • Goals of clinician education should include benefits of LDLT, risk assessment, and timing of transplantation for successful outcomes.
  • The AST Living Liver Donor Provider Tool
Candidate Engagement

• Much of the data regarding candidate engagement and assisting transplant candidates to pursue living donor transplantation currently comes from the kidney literature.

• Key concepts from LDKT literature include education of the transplant candidate and support system on multiple occasions, physician involvement with reinforcement from all transplant team members, use of social media, and peer support.

• Further study is warranted on how best to engage the liver transplant candidates and their broader social networks.

• In the interim, strategies rated as highly impactful and feasible:
  • developing fact-based educational materials on risks and benefit of LDLT for transplant candidates.
  • developing and implementing outreach programs;

• Interventions to focus on the benefits of LDLT, dispelling myths and misconceptions about LDLT, and addressing the stigma associated with certain liver diseases.

• Developing and implementing outreach programs met consensus agreement for impact, feasibility was somewhat lower, likely reflecting needed resources to accomplish community outreach programs.
Lack of Uniformity Regarding Candidate Selection for LDLT

• The lack of understanding of who would really benefit from LDLT is the main limitation to true expansion into offering LDLT more broadly.

• There is a lack of clinical agreement regarding which candidates to encourage to pursue LDLT.
  - Low Meld patients with complications r/t portal HTN
  - Patients with high meld or acute liver failure
  - Hepatocellular Carcinoma patients
  - Emergent indications for liver transplant

• Strategies to increase uniformity in candidate selection for LDLT.
  - Need for further empirical research
    • domains of research focused on better patient selection to optimize patient-outcomes
  - Surgical and medical experience in managing such patients
  - Improvements in education for clinical providers, potential candidates, and their families on the benefits of LDLT for select candidates
Need for Institutional Commitment for LDLT Expansion

- Safe expansion of LDLT requires significant resources and lack of institutional commitment, resources, and infrastructure to support LDLT was an important barrier to expansion

- Strategies to obtain institutional commitment for LDLT
  - Build a dedicated LDLT team with LDLT surgeon, coordinator, medical director, LDLT advocate, mental health, consultation services, and other system-level resources was rated the highest for overall impact across all strategies
  - Efforts to increase volume require sufficient programmatic and financial resources to support all relevant components of the program
    - These include advanced medical expertise in live donation for appropriate patient/donor selection and complex post-transplant management
    - Surgical expertise to perform complex donor and recipient operations
    - Experienced psychosocial clinicians for assessment and potential ongoing intervention operating room and radiology resources
    - Programmatic leadership to ensure collaborative care teams
  - LDLT for Acute Liver Failure requires additional resources for expedited evaluations and surgeries performed beyond normal business hours
Identify practices that have been successful in helping liver transplant candidates pursue LDLT
Lessons learned from Data-driven Kidney LD Interventions

- All interventions show that they increased candidates comfort level with LD and help them to become willing to pursue LD
- Most interventions increased referrals for LD but LDKT is more challenging
- Education that are implemented at multiple times and for greater duration ensure larger and long-term behavioral changes in pursuit of living donor transplant
- Studies report the following challenges to getting candidates to live donor transplant
  - lack of communication between transplant and referring MDs
  - absence of referral guidelines
  - lack of multidisciplinary involvement
  - HCP's lack of information and training
  - negative attitudes of some HCP toward live donor transplant
  - patient-level barriers as defined by the HCP.
- Multiple education settings possible
  - At the transplant center, community education, home based education, culturally competent education
Framework for Engagement*

1. Understand the benefit of LDLT:
   myths and facts

2. Decide what story you want to tell:
   How liver disease has impacted life

3. Educational Interventions:
   Individual mandated sessions
   Group education sessions
   Virtual sessions
   Other community-based sessions
   Use of technology, multi media

4. How to Spread the Word:
   Social media
   Facebook
   Twitter
   Instagram
   Other social networks
   E Blasts
   Newsletters
   Pen and paper
   Word of mouth
   Workplace
   Alumni association
   Book clubs
   Recreational sports leagues
   Church groups
   Other community-based gatherings

*Complements of Swaytha Ganesh MD

13th Annual Living Donation Conference
Presented by the American Foundation for Donation and Transplantation
UPMC Initiatives to Increase LDLT
provided by Swaytha Ganesh Medical Director of Living donor liver transplant program

- Recent publication
  - (LDLT) can play a significant role in increasing the national donor pool.
  - Donor selection criteria are being expanded with the help of surgical innovation, increasing technical expertise, and novel outcomes data.
  - Donor organ pool expansion requires a structured and robust initiative promoting public awareness and education.
  - LDLT volume last 5 years: 72, 91, 56, 60, 28

Expansion of Patient Education Programming Regarding Live Donor Liver Transplantation via Virtual Group Encounters During the COVID-19 Pandemic

Michael Joyce, Luwan Durant, Sukru Emre, Danielle Haakinson, Lenore Hammers, Lisa Hughes, Kara Ventura, Diane Wuerth, and AnnMarie Liapakis*

Yale New Haven Transplantation Center, New Haven, Connecticut

- Virtual patient education and engagement is feasible and can provide support to liver waitlist candidates aiming to pursue LDLT
- Program optimization requires familiarity with and a degree of expertise in provider utilization of technology
- Patient support for implementation is required

Other findings from the literature

- Transplant candidate concerns
  - Barriers associated with their denial and avoidance of the severity of their disease
  - Lack of knowledge, information and awareness of patients and families
  - Reluctance, hesitancy and discomfort to approach and discuss with the potential donors
  - Concerns about the donor’s health
  - Candidates desire to maintain the privacy of their health status
  - Psychological barriers (Guilt, Fear)
  - Risk perception of the donor surgery
Programmatic considerations for improving LDLT acceptance in transplant candidates

- Assess your current programmatic views on LDLT
- How big do you want your LDLT program to be?
- Which candidates does your team believe will get the most benefit from LDLT
  - All candidates
  - Low MELD patients
  - Cancer patients
  - Emergent indications for LDLT
- Will you consider LDLT for acute/urgent cases
  - If so do you have the infrastructure to perform rapid evaluations/surgeries
- Does your transplant team believe that LDLT is the right option?
- What processes are in place or need to be in place for candidate/donor education
- Customize a process based on your current “culture of LDLT” and where you want to be
Discussion