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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

ABSTRACT
During the coronavirus 2019 pandemic we converted our liver transplant waitlist candidate education and support program to a virtual format and expanded it to include ongoing engagement sessions aimed to educate and empower patients to maximize opportunity for live donor liver transplantation. Over a period of 6 months from April 2020 to Sept 2020 we included 21 patients in this pilot quality improvement program. We collected data regarding patient response and potential donor referral activity. Overall, patient response was positive, and some patients saw progress toward live donor liver transplantation by fostering inquiry of potential live liver donors. Optimization of logistical aspects of the program including program flow, technology access, and utilization is required to enhance patient experience. Long-term follow-up is needed to assess impact on the outcome of transplantation rates. Future data collection and analysis should focus on assessment of any potential disparity that may result from utilization of virtual programming. Herein we provide a framework for this type of virtual program and describe our experience.

LIVE donor liver transplantation (LDLT) is underutilized in the United States [1]. The best strategy to increase LDLT is unknown. Data on various programs aimed to increase knowledge of, communication about, and access to LDLT are emerging [2]. Implementation of a formal liver waitlist candidate education program regarding LDLT is a strategy used at the Yale New Haven Transplantation Center [3,4]. The coronavirus disease 2019 (COVID-19) pandemic disrupted transplantation practices and led to temporary suspension of LDLT at many centers in the United States. The COVID-19 pandemic has also transformed health care through telemedicine [5,6].

We aimed to continue engaging our liver waitlist candidates during this time. We converted our currently established liver waitlist candidate education program on LDLT to a virtual format. An Institutional Review Board exemption request was granted given project classification as quality improvement. In this article we report the initial response to this pilot program.

MATERIAL AND METHODS
The education program had previously included an evening session of presentations from providers including hepatologists, surgeons, LDLT coordinators, and social workers as well as previous live donors and LDLT recipients and the distribution of a toolkit our team developed to assist patients in disseminating their story and need for a living donor. The toolkit included a list of suggested community groups for patients and their families to reach out to, useful tips regarding how to seek potential donors using social media, tips on how to create a website, a templated e-mail/letter that patients and their families could use to spread the word among their contacts, and a suggested strategy to spread the word of their need during everyday interactions, accompanied by some of our donor/recipient stories. The presentation was intended to impart an understanding of the unpredictable nature of end stage liver disease, often nonlinear increase in Model for End Stage Liver Disease score, and risk of morbidity and mortality on the liver waitlist. The surgical presentation was intended to describe the surgical procedure of LDLT, risks/benefits of donation (including risk of donor death) and transplantation, and the expected recovery of the donor and recipient. The LDLT nurse coordinator presentation was intended to impart a basic understanding of donor eligibility and the donor process through referral to determination of candidacy. The social work presentation was intended to review the logistics of donation, resources available to support donors and recipients, and to describe strategies that

*Address correspondence to AnnMarie Liapakis, MD, PO Box 208019, 333 Cedar Street, LMP 1076, New Haven, CT 106510. Tel: 203-737-6890; Fax: 203-737-1755. E-mail: annmarie.liapakis@yale.edu

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waitlist candidates might use to begin talking about their need and disseminating information. We hoped that the inclusion of former LDLT donor/recipient pairs offered waitlist candidates and care partners the opportunity to ask questions and receive information from a first-hand account and perspective, and we believed that this was important ethically. The transplant recipients highlighted how they found the courage to talk about their need for a transplant and the importance of continuing to persevere even when a potential donor is declined.

Before inception of this formalized education and support program, LDLT-focused education had been provider dependent during the evaluation process and hepatology follow-up, outside of standard notation of LDLT as an option during the surgical provider presentation of transplant graft options at the surgical evaluation visit.

The virtual program aimed to relay the same content as in the in-person session. We used a virtual meeting platform, Zoom (San Jose, California, United States), which participants accessed from their computer, iPad, or smartphone device. The initial program was held in April 2020 as a 2-hour evening session. As per our routine liver waitlist management, we reviewed our active waitlist weekly and patients deemed eligible for LDLT were contacted by a member of the transplant team via phone and invited to participate in the education session. Patients were encouraged to invite care partners (ie, family, friends). Invitees were queried about their comfort level with a virtual meeting platform and availability of the necessary technology and a suitable device at home. Instructions outlining set-up and utilization were sent to those who requested it. A follow-up invitation to the meeting was sent via e-mail and all print materials that usually accompany the in-person presentation were mailed in advance.

The program was expanded beyond our standard format to focus on better understanding the challenges that patients face in mobilizing and acting to pursue LDLT. This was in the context of feedback from previous attendees to the on-site program since its inception in November 2017, which highlighted the vulnerability and emotional complexity of these patients’ circumstance as they are confronted with their need for a transplant. Many patients reported simultaneously feeling “hopeful/empowered” yet also “overwhelmed/anxious” after the session and stressed the need for ongoing support and engagement. The expansion was developed to include 2 additional virtual meetings and a subsequent formal sign out to participants’ waitlist care team (Fig 1). Sessions were set at approximately 4-week intervals each for 1 hour in the evening.

Each virtual session aimed to accomplish the following 2 goals: follow up to the prior session with 1: prompted open discussion focused on actions taken, barriers noted, and group problem-solving/support and 2. a tutorial regarding utilization of a tangible “tool” (ie, a resource that they may employ in their pursuit of LDLT).

Follow-up session 1 incorporated the “Donor Application,” which was available to our team through a formal research collaboration with Johns Hopkins University as the “tool” [7]. The Donor Application (Johns Hopkins University, Baltimore, Maryland, United States) is a smartphone application designed to help participants create a social media or e-mail post regarding their need for a live donor via a series of question/answer prompts. We used a slide set provided by Johns Hopkins University that was modified by our team to include a mock posting such that attendees were walked through the process and able to visualize what a posting would look like.

Follow-up session 2 incorporated the “15-Second Connection” and “community groups” as the “tools.” The “15-Second Connection” is a concept developed through the Yale Center for Living Organ Donors aimed to help patients feel more empowered when sharing their need for transplantation and opportunity for LDLT. Patients are guided on how to relay the “Why” (my liver is failing), “Need” (my best chance is to find a living donor and I’m sharing my story), “Ask” (can you help me by sharing this information?), and the “Information” (card with transplant center contact info) in everyday social interactions [8]. Attendees were encouraged to brainstorm a list of their community groups within which they may share information regarding their need.

RESULTS

We had 5 groups participate in our pilot program between April and September 2020. This included 21 waitlist candidates as outlined in Table 1. These 21 patients represented approximately 20% of our active liver waitlist population, which averaged 102.8 candidates over the project period. The majority had alcoholic cirrhosis (n = 8, 38%), 3 nonalcoholic fatty liver cirrhosis, 2 primary sclerosing cholangitis, and the remainder consisted of 1 patient in each of the following categories: alcoholic cirrhosis/nonalcoholic fatty liver cirrhosis overlap, primary biliary cholangitis, auto-immune hepatitis/primary biliary cholangitis overlap, Wilson disease, hereditary hemochromatosis, hepatitis C, hepatitis B, and multiple hepatic adenomas. Five of these 21 patients additionally had hepatocellular carcinoma within transplantation criteria.

We have held follow-up sessions 1 and 2 for group 1 and follow-up session 1 for groups 2, 3, and 4. Additional follow-up sessions (session 2 for groups 2, 3, and 4 and session 1 for group 5) are being arranged. All attendees have appeared engaged; however, participation among attendees has varied, with 5 spontaneously speaking, 6 speaking with prompting, and 10 quietly listening/absorbing at the initial sessions. We noted that provider familiarity with the participants and personalized engagement is helpful.

Five waitlist candidates attended our first virtual session (group 1). Four out of 5 had a care partner attend. All but 1 care partner was located at a different geographic location than their respective waitlist candidate. Care partners consisted of adult children, a sibling, a spouse, or a friend of the waitlist candidates. All waitlist candidates used both the audio and video function of the virtual platform. One of the care partners used the audio function only without video. None used the group

![Fig 1. Virtual LDLT Education Program LDLT, live donor liver transplantation.](image-url)
chat function to post an anonymous question. One presenter encountered an unexpected technical issue that impacted the audio component of their presentation. The details regarding the other group sessions are included in Table 1.

Of note, in comparison to the 21 waitlist candidates who attended our virtual program over the 6-month period of April to September 2020, 16 waitlist candidates had attended our in-person program over the preceding 6-month period of September 2019 to March 2020.

Attendees were contacted by their assigned transplant social worker generally within 1 week following their initial session to assess their perspective regarding LDLT and support needs and to gather feedback. A standard format was followed that included both open-ended questioning geared to understand if they felt LDLT was an option for them, steps taken, and barriers encountered, as well as a numerical rating scale for them to grade the usefulness of the program. To date, 17 attendees have been reached, all of whom were receptive to the discussion and provided input; data are reported in Table 2. Overall feedback was positive demonstrated by comments including “it’s a great program,” “I want to be part of the living donor program once I receive a transplant,” “the program is very helpful,” and “informative.” Those who provided a standard numerical rating of the program (1 being worst and 10 best) scored it in the range of 7 to 10, with an average of 8.5. They valued the program and highlighted that there is a need for ongoing education (“good to hear the information again/learned something new”) and the opportunity to continue to include additional care partners. All but 1 attendee was accepting of their need for transplantation, the concept that LDLT was the best option for timely transplantation, and responded that LDLT was an option for them. This attendee stated that he felt LDLT was not an option for him because he had believed that identification of a suitable living donor would take 1 year and noted that he had received 3 calls about deceased donor transplants that did not progress. Once this misconception was addressed, the attendee proceeded with the program, was interactive in the next follow-up session, and noted plans to use “tear off cards” to spread information about his need locally. Many attendees had acted to pursue LDLT noting identification of a champion (n = 9), planning social media posts (n = 6), posting to social media (n = 3), utilization of template the e-mail (n = 1), reaching out to the community (n = 2), creating a web page (n = 1), handing out tear off cards (n = 1), and use of local media (n = 1). Seven attendees noted interest expressed by at least 1 potential donor at that time. Many have subsequently taken additional action, with posting to social media being the most common.

Three attendees specifically discussed COVID-19 as a current barrier in their pursuit of LDLT and expanded on stressors in the context of COVID, including fear of losing income, change in insurance status, and home sale. Five attendees noted identification of appropriate timing/understanding of transplant timing of LDLT program.

| Waitlist Candidate | Complete Sessions | Sessions Support Person Attended | Donor Referrals | Donor Evaluations | Status |
|--------------------|-------------------|---------------------------------|----------------|------------------|-------|
|                    | Initial Session   | Follow-up 1 | Follow-up 2 | Initial Session | Follow-up 1 | Follow-up 2 | Pre | Post | Pre | Post | Pre | Post |
| 1                  | 4/27/2020         | 5/18/2020 | No         | 1               | 0             | N/A        | 0   | 1   | 0   | 0    | DDLtxp 9/13/20 |
| 2                  | 4/27/2020         | No        | 6/16/2020  | 2               | N/A           | 1          | 0   | 2   | 0   | 0    | Waitlist |
| 3                  | 4/27/2020         | No        | 6/16/2020  | 3               | N/A           | 1          | 2   | 38  | 0   | 3    | Donor in evaluation |
| 4                  | 4/27/2020         | 5/18/2020 | 6/16/2020  | 1               | 1             | 1          | 0   | 26  | 0   | 0    | Donor in evaluation |
| 5                  | 4/27/2020         | 5/18/2020 | 6/16/2020  | 1               | 0             | 1          | 1   | 2   | 1   | 0    | Waitlist |
| 6                  | 6/8/2020          | No        | N/A        | 0               | N/A           | N/A        | 0   | 0   | 0   | 0    | Waitlist |
| 7                  | 6/8/2020          | 9/2/2020  | N/A        | 0               | 0             | N/A        | 1   | 0   | 1   | 0    | Waitlist |
| 8                  | 6/8/2020          | Transplanted | N/A        | 2               | N/A           | N/A        | 1   | 0   | 0   | 0    | DDLtxp |
| 9                  | 6/8/2020          | No        | N/A        | 1               | N/A           | N/A        | 0   | 75  | 0   | 4*   | LDLT completed |
| 10                 | 6/8/2020          | 9/2/2020  | N/A        | 1               | 0             | N/A        | 2   | 0   | 0   | 0    | Waitlist |
| 11                 | 6/8/2020          | Deceased  | N/A        | 1               | N/A           | N/A        | 0   | 0   | 0   | 0    | Deceased |
| 12                 | 7/6/2020          | No        | N/A        | 0               | N/A           | N/A        | 0   | 1   | 0   | 1    | Donor in evaluation |
| 13                 | 8/3/2020          | 9/2/2020  | N/A        | 0               | 0             | N/A        | 0   | 0   | 0   | 0    | Waitlist |
| 14                 | 8/3/2020          | No        | N/A        | 6               | N/A           | N/A        | 3   | 95  | 1   | 6    | 3 donors in evaluation* |
| 15                 | 8/3/2020          | 9/2/2020  | N/A        | 1               | 1             | N/A        | 2   | 0   | 1   | 0    | Waitlist |
| 16                 | 8/3/2020          | 9/2/2020  | N/A        | 0               | N/A           | N/A        | 0   | 0   | 0   | 0    | Waitlist |
| 17                 | 9/14/2020         | N/A       | 2           | N/A             | N/A           | N/A        | 0   | 7   | 0   | 1    | Waitlist |
| 18                 | 9/14/2020         | N/A       | 1           | N/A             | N/A           | N/A        | 1   | 0   | 0   | 1    | Waitlist |
| 19                 | 9/14/2020         | N/A       | 1           | N/A             | N/A           | N/A        | 0   | 0   | 0   | 0    | Waitlist |
| 20                 | 9/14/2020         | N/A       | 0           | N/A             | N/A           | N/A        | 1   | 0   | 1   | 0    | Waitlist |
| 21                 | 9/14/2020         | N/A       | 1           | N/A             | N/A           | N/A        | 0   | 0   | 0   | 0    | Waitlist |

DDLtxp, deceased deceased donor liver transplantation; LDLT, live donor liver transplantation; N/A, not applicable. * Donor proceeding as nondirected.
| Waitlist Candidate | Age | Sex | LDLT Option for You | Action Taken | Barriers Noted | Program Rating | Suggestions to Improve | Positive Comments |
|-------------------|-----|-----|---------------------|--------------|---------------|---------------|------------------------|-------------------|
| 1                 | 67  | M   | Yes                 | Used template e-mail, potential donors | Time, support access | N/A           | Prefers in person     | Good to hear info again, program productive |
| 2                 | 59  | F   | Yes                 | Posted to social media, web page | None            | N/A           | None                  | Great program, wants to be part of living donor program once transplanted |
| 3                 | 63  | F   | Yes                 | Champion identified (adult children), potential donors | COVID-19 | N/A           | None                  | Informative |
| 4                 | 56  | M   | Yes                 | Champion identified (wife), planning social media | Time            | N/A           | None                  | Learned more, appreciate donor/recipient pairs that are motivated to give back and share their stories, program very helpful |
| 5                 | 51  | F   | Yes                 | Champion identified (sister), planning social media | Resource access, technology, COVID-19 | N/A           | Technology            | Content was good |
| 6                 | 55  | M   | N/A                 | N/A | N/A | N/A           | N/A | N/A |
| 7                 | 68  | M   | Yes                 | Champion identified (daughter), planning social media | Belief that DDLT will happen | 8 | Requested on-on-one with prior recipient | Very informative, nice people |
| 8                 | 48  | M   | Yes                 | Champion identified (mom), planning social media | Guilt | 7 | None | None |
| 9                 | 34  | F   | Yes                 | Champion identified (mom), posted to social media, toolkit | Resource access | 9 | Minimize interruptions | Really likes the program |
| 10                | 58  | M   | No                  | None | None | N/A           | None | None |
| 11                | 60  | M   | N/A                 | N/A | N/A | N/A           | None | N/A |
| 12                | 66  | M   | Was not yet listed | Planning social media | Waiting to see if listed | 7 | Shorten session | Good information |
| 13                | 62  | M   | Yes                 | Potential donor | None | 8 | Didn't think recipient stories were helpful | Physician talks informative, appreciated assurance of donor safety |
| 14                | 38  | F   | Yes                 | Champion identified (husband), media, reached out to community group, potential donors | Determining right time to proceed | 10 | None | Informative, program great, presenters attentive to questions, well done |
| 15                | 25  | M   | Yes                 | Champion identified (mom and sister), posted to social media, potential donors | None | 10 | None | Informative, toolkit helpful |
| 16                | 59  | M   | Yes                 | Reached out to community groups, handed out tear cards | COVID-19 | 9 | Always room for improvement, no specifics | Program was very helpful, especially enjoyed hearing other patients' stories, |

(continued on next page)
### Table 2 (Continued)

| Waitlist Candidate | Age | Sex | LDLT Option for You | Action Taken | Barriers Noted | Program Rating | Suggestions to Improve | Positive Comments |
|-------------------|-----|-----|---------------------|--------------|---------------|----------------|-----------------------|-------------------|
| y                 | M/F | Yes/no | Planning social media, potential donors | None | None | 10 | 8 | None |
| 17                | 54  | M     | Yes                 | Planning social media, potential donors | None | None | 10 | 8 | None |
| 18                | 53  | F     | Yes                 | Potential donors | None | N/A | N/A | N/A | N/A |
| 19                | 59  | M     | N/A                 | Champion identified (son) | Reluctant to share | N/A | N/A | N/A | N/A |
| 20                | 54  | M     | Yes                 | Technology | N/A | N/A | N/A | N/A | N/A |
| 21                | 67  | M     | N/A                 | Technology | N/A | N/A | N/A | N/A | N/A |

COVID-19, coronavirus disease 2019; DDLT, deceased donor liver transplantation; ESLD, end stage liver disease; JHU, John Hopkins University; LDLT, live donor liver transplantation; N/A, not applicable; MELD, Model for End Stage Liver Disease.
entered the program. Thus far, 15 of 21 waitlist candidates attending the program have had a potential donor’s inquiry. Six of these 15 waitlist candidates had donors referred only before their participation in the program, 5 of the 15 had donors referred both before and after their participation in the program, and 4 of the 15 had donors come forward only after their participation in the program (see Table 1). The 4 waitlist candidates with the largest number of potential donors (26, 40, 75, and 98 for each, respectively) used social media postings and local news media (radio programs and print publications to community groups). Those with the least number of donor referrals include 5 waitlist candidates who most recently attended session 1, so it is possible that the lack of donor activity is related to short follow-up time.

Six program participants have had donors brought in for evaluation. One in this group had a donor approved and 4 have active ongoing donor evaluations. Of note, we are also evaluating 3 potential donors as nondirected donors after they initially called inquiring about 1 of the program participants and subsequently noted a desire to be considered for any patient in need.

There were no live donor liver transplants performed during the pilot program period (April to September 2020) owing to a suspension of the surgical component of the LDLT program because of COVID-19. Three LDLTs have subsequently occurred in the last 2.5 months (October to December 2020). For context, our program performed an average of 7.5 LDLTs per year from 2016 to 2019. Two program participants underwent deceased donor liver transplantation during our pilot program period and 1 unfortunately died while awaiting transplantation.

DISCUSSION

We are planning a team meeting to review each candidate’s participation in the program and readiness to become more engaged with their community regarding their need. Transplant team members will aim to continue to provide one-on-one support and offer “buddying” with a transplant recipient or former live donor as appropriate.

This program will be recurring and was modified in response to feedback received. For example, the initial education set was updated to include a new slide with graphics of the concept of concentric circles of groups through which information may be disseminated and an additional slide with a pie chart illustrating the donor/recipient relationship breakdown for prior LDLT at our center. Potential recipients are encouraged to consider options beyond their immediate family, as we noted that some recipients came with a preconceived notion of restrictions regarding who their potential living donors can be. We have aimed to shorten the initial session from 2 hours to 1.5 hours in response to feedback as well. We have employed a strategy of rotating the faculty members from hepatology and surgery covering the sessions and noted variability in presentation delivery. To standardize the program, improve efficiency, and minimize interruptions we will be creating recordings of the presentation that will be played and have the faculty member present to answer questions reserved for the end of the segment and to help to engage the attendees.

This pilot program demonstrates the feasibility of a virtual education and support program aimed to engage liver waitlist candidates regarding the opportunity for LDLT. Ongoing engagement and support is imperative, as the educational material is too dense for 1 session and pursuit of LDLT is a complex and dynamic process. It is notable that during the in-person and the virtual program, patients reported concern over disclosure of information and feelings of guilt if substance abuse was a contributor, and this is an area that requires specific attention and support.

Initial overall response to a virtual platform has been positive. The virtual platform offers convenience and opportunity for inclusion of participants that otherwise may be restricted by geography. This may ease the burden on patients and their caregivers by allowing them to attend from their home environment without having to consider the time and cost of travel or travel when they may be feeling unwell. The virtual platform does present technical and logistical challenges related to the technology used and the distribution of materials. There is a learning curve for presenters and attendees and requires time to develop expertise to maximize use of functionality. We believe that it is very important to educate all attendees before the sessions about how to use these media platforms in detail to minimize technical challenges and interruptions in real time and allow the interaction to be more fluid. Ongoing support and engagement in follow-up sessions are important, as time and additional interaction is required for participants to apply information and resources to pursue LDLT. Program modification should be dynamic to incorporate patient and staff feedback.

As we develop this program we are aiming to survey attendees online immediately after the session. It may be that some patients might be disadvantaged by lack of technology access and we will need to assure that a disparity does not result. Incorporation of both on-site and virtual venues for education and support program is likely ideal, as some attendees have expressed preference for in-person contact and direct interaction. Programming in a group format may pose a challenge for some and the ability to offer an individualized approach is beneficial. Further follow-up is necessary to determine the sustainability of a virtual education and support program and the impact on patient satisfaction, live donor referral, and transplantation rates.

We recognize the importance of a standardized process and workflow for optimal and unbiased engagement of all eligible waitlist candidates, team communication, and data tracking. As such, we are working to create a report within our electronic medical records that tracks patient demographics, clinical parameters, LDLT eligibility, participation in formalized education, transplant team member touch points of engagement, feedback, and potential donor activity. An automated process, standardized workflow, and dedicated full time employees may optimize the program.

We acknowledge limitations in the reporting of this quality improvement pilot program, including incomplete survey data and short follow-up time. We believe that through this article we have offered a framework for the establishment of a virtual education and support program regarding LDLT for the
transplant community and begun to identify and address barriers to expansion of LDLT.

CONCLUSIONS
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, the development of a standardized workflow, outcomes tracking, and flexibility in program modification.

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