Transplant Candidate Education about Living Organ Donation

*Studies Suggest Patient Education Increases Knowledge, Comfort, Communication, and In Turn, More Living Donor Inquiries, Evaluations and Transplants*

Prepared by the OPTN Living Donor Committee

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Living Organ Donation Educational Programs

A. Introduction

One in four people report they would be willing to be a living organ donor for someone in need.\(^1\) About ninety-five percent of living donors report that they would not change anything about their decision to donate.\(^2\) Yet many patients who need an organ transplant find the idea of asking someone to be their living donor overwhelming.

Among the many disincentives to living organ donation, patient reluctance to talk about it may be among the easiest to eliminate. When transplant centers educate patients about living donation at the right time, in the right place and with the right people, patients feel more knowledgeable and talk about it. That in turn leads to more interactions with others about living donation, and more living donor inquiries, evaluations, and transplants.

While transplant centers’ living donor education programs differ in detail, studies suggest that effective programs have some commonalities. In general, they offer patients:

- Information early in the organ disease process
- An opportunity to include family and friends
- A chance to learn in a comfortable setting
- Simply stated material, whether in written or video format
- Opportunities to talk to living donors and transplant recipients

Educational programs need not, and indeed should not, rely disproportionately on any one category of transplant professional. Studies described below show that multi-disciplinary transplant teams, living donors and transplant recipients help provide effective education.

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Transplant center living donor education programs can also positively influence patients’ use of the internet in connection with organ transplantation. First, living donation education programs can serve as the source of facts when patients begin to consider their options. This is particularly important in light of the extraordinary amount of information and misinformation about living donation accessible on the internet. Second, educating patients and their friends and family about living donation can increase their appropriate and constructive communication about living organ donation on social media: patients who share their need on social media, such as Facebook or Twitter, are more likely to find a living donor than patients who do not.

In sum, transplant centers that teach patients about the benefits and risks of living donor transplantation and how to talk about living donation can help patients avoid prolonged wait times and improve their chances of survival by increasing the number of living donor inquiries, evaluations and transplants.

B. Educational Programs: Scope of Review

This paper summarizes studies of transplant center living organ donor educational programs that are evidence-based or, if they have not yet undergone formal evaluation, have preliminary, suggestive evidence. It is important to emphasize that this is not a systematic review in which only a narrow range of studies are assessed. Rather, the intent is to identify the full range of living donor transplant educational programs that have been developed and evaluated.

C. Educational Program Commonalities: Content, Design Elements and Delivery Teams

Studies suggest effective living donation educational programs have some commonality in content, design and delivery team composition.

Content: Living donation educational programs generally include the following basic subject matters:

- Benefits of transplantation
- Average waiting times for transplantation
- Transplant evaluation process
- Types of transplants and donors
- Transplant outcomes
- Current deceased donation rates
- Differences in donation rates (living and deceased) by race (for minority patients)
- Living donor evaluation process
- Living donor eligibility criteria
- Living donor surgery
- Typical donor recovery
- Risks of living donation
- Benefits of living donation
- Common donor concerns
- Common recipient concerns
- Possible indirect costs
- Helpful resources for transplant patients and living donors

Design Elements. Effective living donation educational programs have some common and relatively simple design elements. They are as follows:
• Include a patient’s family and friends. When family and friends learn with the patient, more conversations happen about the patient’s need, transplant options, and living donation.
• Conduct in a comfortable place. Patients learn more readily in places other than a doctor’s office, such as for example, a library, a community center or a home.
• Provide written material or other media. Providing patients with simply stated factual material about the benefits and risks of living donation increases their understanding and comfort.

Delivery Teams. Effective living donor educational programs include a cross section of transplant professionals and volunteers.
• Transplant Professionals. Educational program delivery teams include diverse professionals such as surgeons, social workers, doctors, nurses, and others.
• Living Donors and Transplant Recipients. Creating opportunities for patients to talk to living donors about their decision, surgery, recovery and subsequent quality of life increases patient comfort. Similarly, creating opportunities for patients to talk with transplant recipients who have been through the process of identifying a living donor reduces patient hesitancy and empowers patients to talk about living donation.

D. Overview of Transplant candidate-centered Living Donor Kidney Transplantation (LDKT) education programs

The programs reviewed below are based on the available evidence, which is almost entirely focused on increasing living donor kidney transplantation. While educational programs focused on liver transplant candidates is critically important as well, there is a lack of evidence for the effectiveness of such educational programs in this population.

Many of the programs described below seek to help transplant candidates identify individuals from their social network who may or may not be potential donors, and include these individuals in educational sessions about LDKT with the potential recipient. A common theme is a focus on supporting and guiding productive communication between the potential recipient and members of his or her social network related to deceased donor kidney transplantation (DDKT) and LDKT, often in the presence of a transplant medical expert to answer questions and concerns for both parties. Some of these programs provide educational materials (e.g., brochures, DVDs) prepared for both transplant candidates and potential donors.

D.1. Programs tested via randomized controlled designs

D.1.a. “House Calls” or Home-Based Education Program

Brief description: Designed for LKDT education, “House calls” is a home-based (HB) intervention in which trained health educators perform a 60 to 90 minute live donor transplantation education session in the candidate’s home, involving family and members of the candidate’s social network. The rationale for conducting the session in the patient’s home is to (a) increase transplantation and living donation knowledge and awareness among members of the patient's social network who are unable or unlikely to attend clinic-based educational sessions, and (b) jump-start the discussion about LDKT and living donation. For most members of the patient’s social network, the HB education provides their first opportunity to learn about transplantation and living donation, and to have their questions answered by a knowledgeable transplant health educator. More knowledge among members of the patient’s family and social
network may facilitate discussions about living donation and reduce the hesitancy of patients to discuss the topic with others. Sessions may also be held in an alternative setting (e.g., another residence, local library or church meeting room) if the patient is uncomfortable hosting the session or if a larger setting is needed to accommodate more guests.

**Supporting evidence:** In one single center, prospective, randomized trial, 169 kidney transplant candidates were randomized to clinic-based (CB) education or CB+HB. Compared to CB alone, more patients who received CB+HB had live donor inquiries (83% vs 64%, \( P=0.019 \)), donor evaluations (60% vs 35%, \( P=0.005 \)) and LDKT (52% vs 30%, \( P=0.01 \)). Both groups demonstrated increased LKDT knowledge after CB education, but HB education led to the largest increase in LKDT knowledge, and also led to greater willingness to discuss LKDT with others and a decrease in LKDT concerns. A secondary analysis provided details on culturally sensitive aspects of the intervention (11): HB education for black patients included at least 1 minority educator and incorporation of race-specific transplant statistics into discussion, and written brochures highlighted minority recipients and their donors. This analysis found increases in both donor evaluations and LKDT at 1 year with CB+HB over CB were larger for black vs white candidates. Notably, the LDKT rate for black patients who had HB education mirrored the LDKT rate that whites had before the intervention; i.e., the intervention appeared to eliminate the initial racial disparity in LDKT at that center.

In a second single center, prospective, randomized trial, 152 black kidney transplant candidates were randomized to the HB intervention, a group-based education session with other patients and their guests in the transplant center, or individual patient counseling. Although rates of LDKT did not differ significantly between the three groups at the 2-year endpoint, patients receiving HB education were more likely than patients in the group-based and individual counseling conditions to have at least one donor inquiry (82% vs. 61% vs. 47%) and evaluation (65% vs. 39% vs. 27%). Patients in the HB group also were more likely to have higher LDKT knowledge, fewer LDKT concerns, and higher willingness to talk to others about donation 6 weeks after intervention.

**Limitations/considerations:** Results of these two trials may be limited by possible self-selection bias among those who gave consent and completed the study (i.e., such patients already may have been thinking about LDKT). Also, in the first trial, there was a higher dropout rate among patients randomized to receive HB education, suggesting further self-selection, and the drop-out rate was higher among black (vs. white) patients. The degree to which trial results are generalizable to other groups of patients and to other regions of the United States is unknown. The costs of training and supporting staff to perform the HB intervention need to be defined; the intervention may be cost-prohibitive for some centers.

**Resources for more information:** James Rodrigue, PhD, Beth Israel Deaconess Medical Center, Boston, MA, jrodrig@bidmc.harvard.edu.

**Relevant references**


D.1.b. “Kidney Team at Home” Home-Based Family Intervention

**Brief description:** In a Dutch adaptation of the “House Calls” approach, the HB intervention comprises two visits at the transplant candidate’s home. In the first (~1 hr) session, the candidate’s social network is diagrammed in order to facilitate understanding of the candidate’s social system, and to guide the candidate in formulating a list of invitees to the second session. In the second (~2.5 hour) session, the educators provide information on kidney disease, dialysis, LDKT, and living donation; stimulate open communication between the patient and family members; and seek to develop consensus on the patient’s goals and how the goals could be achieved with engagement and support of the social network. A notable aspect of the program is the educators’ direct exploration of possibilities for LDKT within the social network.

**Supporting evidence:** In a single center, prospective, randomized trial, 163 patients referred for transplant evaluation or on the deceased donor transplant waiting list were randomized to standard clinic-based (CB) education or standard education plus HB education. All patients were unable to find a potential living donor. Patients in the HB group showed significantly more improvements in LDKT knowledge and communication compared with the control group. Participating members of the patient’s social network also showed significant pre–post increases in knowledge, attitude toward discussing renal replacement therapies, attitude toward donating a kidney, and willingness to donate a kidney, and a decrease in risk perception. When removing patients who died or who received a deceased donor transplant, the researchers found that, compared to those in the standard CB education group, patients who received HB education had significantly more living donor inquiries (32% vs. 74%), evaluations (17% vs. 64%) and actual LDKTs (10% vs. 44%). In a second trial involving patients who had not yet initiated renal replacement therapy, this same research group demonstrated that patients who receive HB education were substantially more likely to receive a pre-emptive LDKT (65% of those who received LDKT within 2 years of intervention, compared to 39% of patients who underwent LDKT at their center during the study period).

**Limitations/Considerations:** The trial results may be limited by possible self-selection bias among those who gave consent and completed study. Of note, the LDKT rate at the study center already was very high (~70%), so patients enrolled in the trial may have faced more substantial barriers to LDKT, given the baseline success at this center. Drop-out was associated with limited social network, suggesting that the intervention may be less effective in patients with fewer family members and friends. This HB program differs from the original version in the United States in two important ways. First, as noted above, it includes two home visits to better facilitate identification of the patient’s complete social network. Second, it focuses exclusively on those patients who are unable to find a potential living donor.
**Resources for more information:** Emma Massey, PhD, Erasmus Medical Center, Rotterdam, The Netherlands, e.massey@erasmusmc.nl.

**Relevant references**


**D.1.c. Talking About Live Kidney Donation (TALK) and TALK-Social Worker Intervention programs**

**Brief description:** These two interventions were developed to address patient hesitation and uncertainty in initiating discussions of LDKT with their social network and the underutilization of preemptive kidney transplantation. The TALK education intervention consists of a video and booklet on LDKT and living donation. The 20-minute video includes ethnically diverse patients and families describing their experiences discussing and pursuing LDKT, and transplant professionals describing factors for patients/families to consider. The booklet encourages patients not yet on dialysis to talk to family and health care providers about LDKT, with examples of model conversations and sources of additional information. Patients can choose to review the video and booklet on their own or with a social worker, who is available to discuss the content and answer any questions. Patients are also encouraged to share the materials with members of their social network. The TALK-social worker intervention combines the video/booklet with two sessions (both ~1 hour long) delivered by a social worker. In the first session, the social worker distributes the video and booklet and then helps the patient identify barriers to considering or pursuing LDKT. The patient is asked if they would invite family/friends to a second session. At the second session the social worker helps social network members to identify barriers to LDKT and living donation and to describe prior discussions about living donation. Problem-solving and motivational interviewing techniques are employed at both sessions. These sessions are conducted either in the patient’s home or in the transplant center.

**Supporting evidence:** In this trial, 130 patients were randomized by site (nephrology practice) into three study arms (usual care with nephrologists, and one of the two TALK conditions). Patients eligible for the intervention were drawn from academically affiliated or community nephrology practices, and were not yet on dialysis (although they may have had a transplant evaluation). The primary outcome was whether patients engaged in any one of 5 behaviors reflecting discussion about and/or pursuit of living donor transplantation (discussions with family, discussions with physicians, initiating transplant evaluation, completing transplant evaluation, identifying a potential living donor). Patients’ predicted probabilities of engaging in at least one behavior over the 6 months of follow-up were 30% in usual care, 42% in TALK-education and 58% in TALK-social worker intervention. Additional analyses showed that, beyond this three-group difference, the two TALK groups did not differ from one another. The most common behaviors engaged in were talking to family and physicians. In additional analyses of secondary
outcomes, no differences were observed between groups in interest in or concerns about living donor transplantation.

Limitations/Considerations: The follow-up period was relatively brief, and the study did not consider actual receipt of LDKT as an outcome. The educational materials did not provide extensive information on risks and benefits of LDKT, and financial barriers were not considered in the TALK interventions. The study population was well educated, mostly insured, and pre-dialysis. Only 67% of patients in the TALK-social worker intervention condition attended both sessions, and 19% of patients attending the second session did not bring family/friends. More complete uptake of the interventions may have been limited by the high percentage of patients with an eGFR >20 who may not have been “primed” or ready for this focused discussion on LDKT and living donation.

Resources for more information: DePasquale et al. include an Appendix listing questions used by the social worker to identify barriers to LDKT experienced by the patient and family/friends. TALK materials are also available at http://ckddecisions.org/.

Relevant references

D.1.d. “Living ACTS” (About Choices in Transplantation and Sharing)

Brief description: Living ACTS (About Choices in Transplant and Sharing) was designed to be a culturally sensitive intervention targeted to African-American patients. It was developed based on a conceptual model that emphasizes the need to address both “surface” characteristics relevant to a given cultural group (e.g., by including people, places and language familiar to and preferred by the target audience) and more deeply rooted elements that may influence behavior (e.g., the influential roles that family discussion and family impact play in many African-Americans’ decisions regarding healthcare). The intervention consists of a DVD and booklet. The DVD features African-American patients, families and healthcare professionals and addresses the impact of LDKT on families, how family decision making around living donation may occur, and financial resources for LDKT. The booklet provides additional information such as web links and tips for starting conversations with family members. The intervention was designed to address inadequacies of existing educational efforts in addressing unique concerns and issues in African American patients that may serve as barriers to pursuit of LDKT.

Supporting evidence: In this single-center randomized controlled trial, 296 black adults who presented for transplant evaluation were randomized to receive exposure to standard education plus the Living ACTS intervention or standard transplant education plus an attention-control DVD about exercise. Standard education consisted of a web-based course (transplant-specific education) that had to be completed before the evaluation. Knowledge about living donation
and willingness to talk to family about living donation were assessed before randomization, immediately after education, and 6 months later. Subjects in the Living ACTS group showed a significantly greater increase in knowledge about living donation immediately after the intervention than did controls and this was maintained through the 6 month follow-up period. Although the intervention group showed significantly higher willingness to talk with family about living donation, this difference was evident at baseline and did not change over time. Intervention participants endorsed greater perceived benefits of living donation than did controls immediately after the intervention, but this effect disappeared by the 6 month follow-up.

**Limitations/Considerations:** Although the authors note that 96% of patients approached agreed to enroll, the sample was one of convenience and the potential for generalizability is unknown. In addition, the analyses did not follow an intent-to-treat approach and included only those with complete follow-up data. Because no information was collected from patients on educational activities or interactions with family regarding donation after they returned home, it is difficult to speculate on reasons why the intervention affected knowledge but not other outcomes over the 6 month follow-up period.

**Resources for more information:** Kimberly Jacob Arriola, PhD, Emory University, Atlanta, GA, kjacoba@sph.emory.edu.

**Relevant reference**


**D.1.e. Culturally targeted website for Hispanic transplant candidates**

**Brief description:** The authors developed a bilingual, culturally targeted website (Infórmate) for Hispanic transplant candidates and members of their social network. Focus groups with Hispanic kidney transplant candidates, living donors, dialysis patients, and members of the general public led to content development. The website is in Spanish and English and was designed to overcome many of the known sociocultural barriers to LDKT in Hispanics, including misconceptions about living donation, language barriers, immigrant status issues, financial concerns, and distrust of the healthcare system. The website also was designed to extend the Northwestern Memorial Hospital's Hispanic Kidney Transplant Program, which is described below and is a unique clinical program providing care to Hispanic transplant patients.

**Supporting evidence:** In a two-center randomized controlled trial, 282 new kidney transplant candidates were randomized to receive access to the website or to usual care. Usual care consisted of attending a transplant education class on the day of their initial evaluation. Patients and their family members in both groups received this standard care; however, one group was also given access to Infórmate before attending the class. Findings showed that patients and family members in both groups had significant improvements in LDKT knowledge from pre-intervention to the 3-week follow-up assessment; however, the knowledge gains were much more substantial for patients who were assigned to website group.
**Limitations/Considerations:** The majority of study participants were family members of the transplant candidate. Presentation of the knowledge gains are not broken down by participant type, thus it is unknown whether the knowledge gains observed occurred equally for both patients and family members. There is also the possibility of contamination in this study, since the website intervention occurred before a group education session including all study participants. Patients and family members who had access to the website may have shared its content and information with patients in the usual care group, thus potentially suppressing the effects of the website intervention. Finally, the study evaluated changes in knowledge only, so it is not known whether the website impacts rates of living kidney donation or LDKT.

**Resources for more information:** Elisa Gordon, PhD, Northwestern University Medical Center, Chicago, IL, e-gordon@northwestern.edu.
www.informate.org [Infórmate: Inform Yourself about Living Kidney Donation for Hispanics/Latinos] [Infórmate: Infórmate Acerca de la Donación de Rinón en Vida para Latinos]

**Relevant references**

**D.1.f. Written educational materials followed by a structured educational session**

**Brief description:** This is an intervention in which patients newly referred for transplant evaluation are mailed written materials about living kidney donation and the benefits of LDKT. About two weeks later, patients and their invited guests attend a 2-hour educational session in the transplant center. This session, which includes 3 to 5 others patients and their invited family members, uses a problem-based learning format and is facilitated by a transplant nurse coordinator and nephrologist. In addition to providing didactic information about the advantages and disadvantages of ESRD treatment options and living kidney donation, patients and family members form smaller groups to problem-solve common scenarios pertaining to LDKT. For instance, this includes finding strategies to overcome barriers to living donation and role playing how to ask others about living donation. At the end of the learning session, there is a question and answer session with a LDKT recipient and former living kidney donor.

**Supporting evidence:** In this single-center randomized controlled trial, 100 patients who presented for their initial transplant evaluation were randomized to receive either usual care or the enhanced LDKT educational program. Usual care consisted of informal discussions with providers about all aspects of kidney transplantation as patients progressed through the evaluation process. The primary outcome was whether the patient had a potential living kidney donor contact the transplant center to initiate evaluation within 3 months after the intervention. Also, patients completed a living donation knowledge questionnaire and an ESRD treatment
preference questionnaire prior to intervention and again 2 weeks following the intervention. The two groups did not differ significantly in the number of potential living donors who contacted the transplant center. Extending the follow-up period to 6 months also did not yield any significant between-groups difference. Patients in the intervention group who had not identified LDKT as their treatment preference initially were more likely to state that this was now their primary treatment preference 2 weeks after the intervention.

Limitations/Considerations: As the authors acknowledge, the study was under-powered to detect any significant differences between the two groups. While targeting enrollment of 100 patients per group, they were able to enroll only 50 per group. Selection bias is an important limitation because those who have made a decision to seek transplant evaluation may have already identified this type of intervention as preferable. Although living donation knowledge was assessed, these results are not reported. Details are lacking regarding the specific nature of usual care at this particular center, thus making it difficult to determine the nature and dose of any LDKT information they may have received. Finally, the drop-out rate for the intervention was very high (30% did not attend the education session), suggesting further self-selection.

Resources for more information: Brenda R. Hemmelgarn, MD, PhD, Division of Nephrology, Foothills Medical Centre, Calgary, Alberta, Canada, bRENda.hEmmelgarn@albertahealthservices.ca

Relevant reference


D.2. Programs supported by observational (non-randomized) studies

Several of the programs described above offered sessions to candidates and their families in their homes or at sites separate from the transplant center. A variety of additional programs have been developed that may be offered at transplant centers or elsewhere but that have not yet undergone testing in randomized controlled trials. Thus, whether or not these programs are effective in educating patients or assisting them to identify living donors has not been fully established. These programs have relied on quasi experimental designs (e.g., use of historical controls or comparison groups), or simple one-group pre-post observational designs, often in small pilot samples. However, the programs are noteworthy for their creativity in developing strategies using peer-mentors, social media tools, and mobile decision aids.

D.2.a. Patient Navigators in Community-Based Nephrology Practices

Brief description: This intervention is predicated on the assumption that early contact with transplant candidates allows for early education about transplantation and a higher potential for LDKT, particularly pre-emptive transplants. The overarching goal of the program is to help patients progress through the referral, evaluation, and transplantation process. Social workers are placed in community-based nephrology practices after receiving training in transplantation, living donation, and cultural sensitivity delivered by transplant physicians, nurse coordinators, and social workers. They seek to establish relationships with potential transplant candidates,
provide support and individualized transplant and living donation information to patients and family members, and address barriers to possible LDKT and living donation. The patient navigators meet with patients before or after their appointment with the nephrologist and, upon request, scheduled additional individual appointments with patients.

Supporting evidence: In a non-randomized pragmatic observation study conducted over a 58-month period, patients referred to the transplant center from nephrology offices (n=2) with a patient navigator were compared with patients referred from nephrology offices (n=90) without patient navigation. The investigators retrieved outcomes data on 2,722 propensity score matched transplant candidates and 424 propensity score matched transplant recipients at their center. Patient navigators had a mean of 6 contacts with patients (range = 1 to 32). Patients from a nephrology practice with a patient navigator were more likely to have a potential living donor inquiry and a living donor undergo initial screening compared to patients from nephrology practices without patient navigation. However, the two groups did not differ significantly on the number of patients who had a living donor fully evaluated or LDKT.

Limitations/Considerations: Treatment integrity was not measured in this study and it is unclear whether the intervention was delivered as intended. Additionally, the “dose” of the intervention was not standardized, which may have impacted observed outcomes, although this was not examined. It may be that patients who had more patient navigation contacts may have progressed more rapidly through the transplant evaluation process and had more interest in LDKT. Patient navigators were hired as full-time employees, which may make the intervention cost-prohibitive for many transplant programs to adopt and replicate.

Resources for more information: Prabhakar Baliga, MD, Medical University of South Carolina, Charleston, SC. baligap@musc.edu

Relevant reference

D.2.b. Living Donor Family Education Program

Brief description: Designed and then refined across a series of publications, this program is offered at the transplant center to “recipient families,” which included relatives as well as friends of candidates for kidney or simultaneous kidney-pancreas transplant. The intervention is offered during the evaluation process (but the exact time point is not specified). The intervention consists of a didactic presentation and discussion led by one of several program nurse coordinators, each of whom is experienced and familiar with the living donation process and related literature. The intervention also includes an educational video that incorporates information on the surgical procedure and risks, as well as perspectives and comment from donors on the pre-operative testing experience. The video seeks to give perspectives from donors demographically similar to the population served by the transplant center (which was predominantly African American and older). The video has been modified over time but has generally been 8 to 11 minutes long. Overall, the program seeks to address problems in the transplant center’s past educational efforts, including: 1) limited and inconsistent information on
living donation were provided to transplant candidate families; 2) education was not integrated into the program’s evaluation and care process.

Supporting evidence: In an initial publication, after the program had been offered for over one year, the investigators compared the percentage of patients who had potential living donors submit blood samples to determine candidacy in the group receiving the new program vs the percentage for patients before the program existed. Among 1,363 patients registered on the transplant waiting list during the 54-month study period, the authors found that a significantly higher percentage of patients had at least one potential living donor tissue typed after versus before the program was implemented (39% vs. 33%). The program was particularly effective for blacks and older patients, who had higher rates of living donor tissue types after versus before program implementation (36% vs. 28% for blacks; 31% vs. 19% for older patients). In additional analyses, the authors observed that the rate of kidney transplant was significantly higher after the program’s initiation than before, but post-transplant survival rates were not affected. In subsequent analyses over a longer time period of about 4 years after intervention program inception, the authors continued to find differences favoring increased rates of living donors submitting blood tests after program inception compared to before inception, but findings were inconsistent in terms of subgroup effects.

Limitations/Considerations: The results are primarily limited by reliance on a historical comparison group; rates of potential living donors submitting blood tests may have increased naturally over time even without the intervention. In addition, although the authors conclude that it is important to have ethnically appropriate teaching materials, they did not directly evaluate whether that specific component of content contributed to any effects. The study included only a single center.

Resources for more information: Clarence Foster, MD, University of California, Irvine, Orange, CA. foster@uci.edu.

Relevant references


D.2.c. “Seminars on Saturdays” Program (19)

Brief description: This program represents a revision of an existing program offered by a single transplant center, based on attendee feedback and analysis of logistical barriers felt to have limited previous participation in education programs. The intervention is targeted toward (but not exclusive to) preemptive kidney transplantation, and consists of formal talks, facilitated discussion during break-out sessions, audiovisual aides, and an information packet, along with follow-up contact by a transplant coordinator to determine if more information is needed. The program is conducted by a multidisciplinary team including surgeons, other physicians, and nursing staff including transplant coordinators, clinical nurse, pre-dialysis nurse specialists,
dialysis staff, counselors, and a team of 10-12 volunteers (per seminar), including kidney recipients and donors. The inclusion of testimonials from these volunteers, who varied in type of relationship to the patient and age/gender/ethnicity, is viewed as a critical component of the program. The program is offered every 2 months (6 times per year) on a Saturday to all pre-dialysis patients and their family/friends, as well as all patients on the national waitlist for a kidney, and all dialysis patients not yet waitlisted but deemed suitable by their care providers for transplant. The program seeks to address the following problems: 1) lack of access to information and misconceptions about living donation, both of which were seen as principal barriers that prevented potential recipients and donors from coming forward for transplantation; 2) a need to improve the quality and way information was imparted in order to increase preemptive living donor transplants.

**Supporting evidence:** The program was revised in 2006 and began to be offered and evaluated in 2007. Analyses are based on comparisons of outcomes annually from 2005 to 2010, and the data come from the single center where the program was offered. The investigators note growth in program attendance. They note a significant increase in the percentage of LDKTs that were preemptive at their center (from 28% to 44%). The percentage of non-blood-related donors among the total number of living donors increased from 28% to 41% (no test reported). They also report a significant increase in preemptive LDKTs that were from non-blood-related donors transplants (from 25% to 58%). They report an increase in in the percentages of minority donors from 39% in earlier years to 52% in later years (no test reported).

**Limitations/Considerations:** The results focus on a comparison of annual data and do not directly compare outcomes in individuals who attended vs. did not attend an intervention session. The changes over time cannot be specifically attributed to launching a revised intervention. The analyses do not appear to specifically analyze trends over time but instead compare rates across 6 nominal groups (defined by year). Thus, they report a difference across the 6 groups defined by year but do not test directly that the percentages monotonically increase by year. Some effects are not subjected to any statistical test.

**Resources for more information:** Wendy Brown, MD, Hammersmith Hospital, London, UK. wendy.brown@imperial.nhs.uk

**Relevant reference**

**D.2.d. “Live Donor Champion” (LDC) Program**

**Brief description:** The LDC program was designed on the premise that not requiring the kidney transplant candidate to try to find their own living donor but giving them a “champion” or advocate on their behalf would lead to more offers of LDKT. The LDC program focuses on the removal of three specific barriers to LDKT: 1) discomfort discussing such a sensitive subject; 2) fear of asking someone else for an organ, and 3) limited knowledge about the live donation
process. In the LDC program, each wait-listed candidate identifies one person to be their ‘Live Donor Champion’, who will be provided with educational materials, business cards, and other resources from the transplant center. The role of the LDC is to improve comfort in initiating conversations and spreading awareness about the patient’s kidney failure and about live donation with the ultimate hope of helping the patient to identify potential live donors. Anyone over 18-years of age that speaks English is eligible to serve as a LDC; the LDC is usually a spouse, significant other, family member, or friend of the patient. The program comprises 6 meetings held once per month. Each meeting is approximately two hours, focuses on a different topic. Topics include introduction to kidney transplantation and live donation, how to initiate a conversation with potential live donor candidates, identifying a social network, and sharing success stories with a live donor and recipient panel. The LDC is encouraged to use the information and skills learned at each session to begin looking for potential donors. Participants are asked to keep a monthly log of their progress and are also encouraged to record what worked well and what did not in an effort to provide as many opportunities for feedback to program coordinators.

Supporting evidence: Published pilot experience is based on a single-center prospective cohort study of 15 adult kidney transplant candidates who had been on kidney transplant wait-list for at least 3 months and had no potential living donors at the time of enrollment. Comfort in initiating a conversation about transplantation increased over time for LDCs. Twenty-five potential donors contacted the center on behalf of LDC participants; four participants achieved LDKT and three additional participants had donors in evaluation, compared to none of the matched controls, at the time of publication.

Limitations/Considerations: This was a non-randomized pilot study with a small number of patients. It was subject to selection bias because enrollment was voluntary. It is plausible that the LDC participants were more motivated and enthusiastic than the wait-list population as a whole. While nearly half of the LDC patients were Black, it is unknown whether the intervention yielded the same benefit regardless of race. The lengthy duration of the intervention (6 months) is an important limitation, especially for those patients seeking pre-emptive LDKT. Finally, patients with smaller social networks may benefit less from the intervention, particularly if they are unable to identify a LDC.

Resources for more information: Dorry Segev, MD, Johns Hopkins University, Baltimore, MD. dorry@jhmi.edu (http://www.hopkinsmedicine.org/transplant/patient_information/live_donor_program.html)

Relevant reference

D.2.e. Hispanic Transplant Program Education

Brief description: This intervention was designed to be a linguistically and culturally competent educational program for Hispanic transplant candidates, using an established framework for standardizing the measurement and reporting of high quality, culturally competent care. The
program sought to address some of the underlying reasons for disparities in LDKT rates in Hispanics. The intervention consists of two educational sessions offered at the time of patients’ evaluation for transplant at the center. The first session includes both patients and family members (or friends) in which a Hispanic transplant surgeon presents information about transplantation, donation risks and benefits, and alternatives. The second session includes only family members and is focused on cultural concerns and misconceptions.

**Supporting evidence:** The study used a pre-post design in which 43 patients and 70 family members completed pre-intervention measures, received the intervention, and then immediately completed post-intervention measures. The attitudes of family members and friends about being a living kidney donor were also assessed. There was a statistically significant increase in knowledge for both patients and family/friends. Knowledge was higher at post-test among patients than in family/friends, and among younger and more educated individuals. Pre-to-post attitude change was noted in some areas: patients became more motivated to pursue LDKT and felt more favorably about it. Family/friends increased in willingness to become living donors and became more motivated to begin the living donor evaluation. High levels of satisfaction with the intervention were noted.

**Limitations/Considerations:** The resources needed to mount this type of intervention may not be available to all transplant programs. The study did not include a comparison group, the sample was a convenience sample, and the analyses focused on a completer-only analysis. Thus, the robustness and generalizability of the findings is unknown. There was no follow-up period to determine if knowledge and attitudes were maintained over time. It also not clear from this study whether improved attitudes regarding living donation and motivation to pursue living donation translated into an actual increase in the number of living donor inquiries among those family/friends. These limitations notwithstanding, this is an innovative program targeting a patient population with known disparities in LDKT.

**Resources for more information:** Elisa Gordon, PhD, Northwestern University Medical Center, Chicago, IL, e-gordon@northwestern.edu.

**Relevant reference**

**D.2.f. Educational Intervention Based in Peer Experiences**

**Brief description:** This intervention was developed to expose liver transplant candidates (and potential living liver donors in their social network) to the experiences of former living liver donors. It was thought that exposure to actual living liver donors, something that is lacking in transplant candidate education, may help transplant patients to improve their knowledge about living donation and to feel more comfortable discussing donation with others. The intervention includes a booklet and DVD (available in 6 languages), and a website that includes the same written and video materials. In the materials, the former living liver donors discuss their experiences, including views about the surgery, recovery, costs, employment, and life after donation. The materials also include direct quotes from donors concerning what information
they would give to individuals considering living liver donation. Although the intervention is designed to be delivered to the transplant candidate in the transplant clinic, it can be mailed to patients. Also, patients are encouraged to share the materials with potential living donors in their social network.

Supporting evidence: Drawing on liver transplant candidates from 5 transplant centers, the investigators compared 338 patients who received the intervention to 437 patients who received “usual education” at those same centers before the intervention was offered. Primary outcomes were patients’ living donation knowledge and feelings of self-efficacy to discuss living donation with others. Patients in the intervention group reported significantly more knowledge than those in the comparison group, and they reported higher levels of self-efficacy regarding ability to discuss living donation with others. Among those in the intervention group who were known to either have viewed or not viewed the intervention materials, those who viewed them showed significantly higher self-efficacy. Patients in the intervention group were significantly more likely to have talked about living donation with others than those in the comparison group. Also, the total number of family/friends who presented for donation consideration and the number of actual living donors both increased over a 3-year period, although no statistical testing between groups was done.

Limitations/Considerations: The results are primarily limited by reliance on a historical comparison group; other elements may have led to the differences observed in knowledge and self-efficacy, and the numbers of living donors who were evaluated and who actually donated may also have changed over time due to other factors. The investigators do not report whether patients who completed the self-report outcome measures differed from those who did not complete the measures. The self-report outcome measures did not employ items known to be valid and reliable. Only 27% of those in the intervention condition report viewing the intervention materials; 58% did not view them and for 15% it was unknown as to whether they viewed them or not. Thus, the uptake rate of the intervention is quite limited overall.

Resources for more information: The written and video information are available at: http://www.nyclt.org/living_donor/ (last accessed 4/5/16).

Relevant reference

D.2.g. Provision of Audiovisual and Written Educational Materials Pre-dialysis patients

Brief description: A predialysis education program (PDEP) was developed in Turkey and is described as a training kit using visual and written information cards and consisting of 6 modules targeted towards the degree of kidney disease experienced by patients in chronic renal failure. Modules 1 through 3 address general considerations and treatment recommendations for all patients regardless of level of kidney disease; and remaining modules address peritoneal dialysis, hemodialysis and kidney transplantation, respectively. The problems that the PDEP was designed to address included the need to (1) inform and educate patients about their disease and treatment options before dialysis, and (2) reduce treatment complications, increase
treatment compliance, and start treatment in a planned way in order to avoid emergencies. An implicit hypothesis was that PDEP would have an impact on preemptive transplantation with a living donor.

**Supporting evidence:** The intervention was evaluated in a single university hospital in Turkey in a non-randomized retrospective analysis. Among 88 living donor kidney transplant recipients over an 8 year period, 61 patients who received PDEP were compared to 27 patients who received transplants before PDEP was available. Significantly more PDEP patients had preemptive LDKT than those who did not receive PDEP (43% vs. 19%). They were more likely to receive these transplants from spouses, siblings and non-parent relatives, and less likely to receive these pre-emptive transplants from parents than non-PDEP patients.

**Limitations/Considerations:** Very limited detail is available regarding the conceptualization, development or specific content of the PDEP modules. This would make it difficult to replicate in other populations beyond the original group considered in Turkey.

**Resources for more information:** Erdem Cankaya, MD, Department of Nephrology, Medical School, Ataturk University, Erzurum, Turkey.

**Relevant reference**

**D.2.h. Center-based LDKT education for Black and Hispanic patients**

**Brief description:** The Living Donation Education (LDE) program was developed to address common barriers to LDKT and living kidney donation among Black and Hispanic patients. The intervention is delivered in two phases, both occurring at the transplant center. In Phase I, patients and family members attend a formal education session in which a healthcare provider progresses through a series of slides on alternative ESRD treatments, the benefits of LDKT, living and deceased donation, specific information focused on living donation (eligibility criteria, surgery, risks, outcomes), the concept of a live donor champion, and strategies to identify potential living donors. All participants receive a take-home booklet mirroring information presented during the session. In Phase II, patients and family members are invited back to the transplant center to meet with a living donor and recipient pair who share their experiences and answered questions. Both educational sessions and take-home materials are provided in English or Spanish, based on patient preference.

**Supporting evidence:** In a single-center study, patients on the kidney transplant waiting list who met study eligibility criteria were informed about the LDE by telephone and encouraged to attend the program. The authors tracked the number of patients who attended the LDE and examined whether they had a higher likelihood of living donor inquiries, evaluations, and transplants compared to patients who did not attend an LDE session but who attended the transplant program’s regular patient support group. There were no statistically significant differences between the two groups of patients on any of the living donor or transplant
outcomes. Also, the two groups did not differ on changes in LDKT knowledge, willingness, concerns, or readiness.

**Limitations/Considerations:** The study is limited by limited statistical power, non-randomized design, selection bias, and cross-contamination. Of the 294 candidates that were called, 75 patients attended the Phase I educational session and only 7 patients returned for the Phase II session. Interest in attending an intervention focused on LDKT was very low with this minority population. The study originally was designed to also examine the home-based education program developed by other; however, this group was dropped after only one patient chose to participate in a home-based education session. It is possible that interest in LDE was limited because the transplant program in which the study occurred was not able to conduct LDKTs for one year due to a living donor death. This occurred shortly after study initiation. While the program was permitted to evaluate potential living donors, the restriction of performing LDKT certainly could have adversely impacted study participation rates and outcomes. Also, half of the patients receiving the LDE intervention also participated in the “control” condition by attending one or more support group sessions.

**Resources for more information:** Liise Kayler, MD, Erie County Medical Center, Buffalo, NY, lkayler@ecmc.edu.

**Relevant reference**

**D.2.i. Social media / Facebook**

**Brief description:** Researchers recently developed and pilot-tested a Facebook smartphone app that enables transplant candidates to share their need for a live donor through social media, providing an indirect means for communication with a broad social network. Grounded in prior literature, clinical judgement, ethicist oversight and feedback from patient focus groups, the app provides step-by-step instructions for creating a Facebook post detailing an individual’s struggle with organ failure and their need for a living donor. Links to sources of vetted information on the risks, benefits and processes of live donation are also included.

**Supporting evidence:** In the pilot study among 54 adult transplant candidates without potential live donors at the time of enrollment, the majority of candidates using the smartphone app reported it to be “good” to “excellent” with respect to the installation process, readability, simplicity, clarity and content. Notably, compared to matched controls, patients using the app were nearly 7-times as likely to have a potential donor come forward on their behalf over 10-months after enrollment.

**Limitations/Considerations:** Limitations of this initial study include the small sample size, non-randomized design, and potential selection bias from enrollment of more motivated or technologically sophisticated candidates – but importantly, the pilot report demonstrates a promising role for well-designed social media tools to provide an inexpensive and easy-to-use
strategy to increase identification of potential living donors. Future studies should assess the impact of the Facebook app on conversion of donor referrals to LKDTs, cost-effectiveness (including consideration of staff time for referral intake and screening), and the quality of patient shared-decision making about transplant options and donation.

**Resources for more information:** Andrew Cameron, MD, Department of Surgery, Johns Hopkins University School of Medicine, Baltimore, MD, acamero5@jhmi.edu.

**Relevant reference**

**D.3. Emerging Programs**

Additional programs have also been described but have either received no formal evaluation to date or data have yet to be published. This white paper will be updated with evidence as studies and trials are completed, and outcomes are reported.

Examples of emerging programs focused on LDKT and living donation include the following:

**Peer mentoring (National Kidney Foundation)**
- https://www.kidney.org/patients/peers

**Explore Transplant at Home / Your Path to Transplant**

**Mobile Clinical Decision Aids**

**ELITE Program**