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Live Donor Champion: Finding Live Kidney Donors by Separating the Advocate from the Patient¹

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Abstract

Background—Lack of education and reluctance to initiate a conversation about live donor kidney transplantation (LDKT) is a common barrier to finding a donor. While transplant candidates are often hesitant to discuss their illness, friends or family members are often eager to spread awareness, and are empowered by advocating for the candidates. We hypothesized that separating the advocate from the patient is important in identifying live donors.

Methods—We developed an intervention to train a Live Donor Champion (LDC) (a friend, family member, or community member willing to advocate for the candidate) for this advocacy role. We compared outcomes of 15 adult KT candidates who had no prospective donors and underwent the LDC intervention with 15 matched controls from our waiting list.

Results—Comfort in initiating a conversation about transplantation increased over time for LDCs. Twenty-five potential donors contacted our center on behalf of LDC participants; four participants achieved LDKT and three additional participants have donors in evaluation, compared to zero among matched controls ($p < 0.001$).

Conclusions—Transplant candidates are ill-equipped to seek live donors; by separating the advocate from the patient, understandable concerns about initiating conversations are reduced.

Keywords

Education; Live Donor Transplantation; Communication Strategies

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INTRODUCTION

Despite improved graft function and longevity, live donor transplants are only a moderate proportion of kidney transplants (KT) performed in the United States (1). Additionally, live donation rates have remained relatively stable over the past decade, despite evidence that as many as 1 in 4 people would be willing to donate if they knew that a family member, community member or even a stranger were in need of an organ (2). Previously identified barriers to finding a live donor include lack of education and knowledge about live donation, as well as hesitance to initiate a conversation about live donation (3–5). Barnieh et. al demonstrated that knowledge of how to ask someone to donate was the most prevalent barrier identified by transplant candidates (6).

In general, transplant candidates are hesitant to discuss their illness and the difficulties associated with dialysis, and are therefore reluctant to pursue live donation (7–9). However, friends or family members are often eager to spread awareness about their loved one's plight, and are empowered by advocating for them (10–12). Successful campaigns using media and other modalities of communication on behalf of patients have been led by parents, spouses, and other family members (13–14).

We hypothesized that separating the advocate from the patient may alleviate barriers experienced by transplant candidates in initiating conversations about live donation and identifying live donors. We conducted a prospective study of a novel intervention that facilitated this separation of advocate from patient. Namely, each patient was paired with a live donor champion (LDC) - a friend, family member or community member willing to advocate for the patient. We compared participants with matched controls from our waiting list to explore the ability of the LDC intervention to attenuate the communication barrier experienced by transplant candidates and lead to increased live donor kidney transplantation (LDKT).

RESULTS

Study Population

Participants were on average 57 years old (SD 9.9), 33% male and 67% married. Matched controls were similar in demographics, including age, gender, race, time on waiting list, blood type, diabetes status, cause of kidney failure and education level (Table 1A). LDCs were on average 52 years old (SD 13.8) and 47% male. Most LDCs were spouses (67%) while the remaining were other family members (20%) or friends (13%) (Table 1B). All patient-LDC pairs were of the same race.

Barriers to Live Donation

LDCs reported many barriers to identifying a live donor such as fear of initiating a conversation (100% of LDCs reported this barrier at the beginning of the study), being embarrassed to ask others about donation (60%), not knowing who to ask (80%) and lack of knowledge about kidney failure and live donation (80%). In openended questions, participants additionally mentioned concerns about religious and cultural issues, for example living donation among Jehovah's witnesses. All participants wanted more educational materials and assistance with their conversation skills. Additionally, most participants wanted a support group atmosphere and available internet resources.

Comfort in Initiating a Conversation about Live Donation

At baseline, LDCs were more comfortable approaching a family member (mean score 1.2) and least comfortable approaching a stranger (mean score 0.4). Over the course of the study,

LDCs became more comfortable overall initiating a conversation about live donation (mean baseline comfort score 0.92 and mean final comfort score 1.96, $p<0.001$; Figure 1). By subgroup, LDCs became more comfortable approaching friends (baseline 1.2 and final 2.16, $p=0.03$), community members (baseline 0.8 and final 1.8, $p=0.04$), religious group members (baseline 1.0 and final 2.0, $p=0.001$), and strangers (baseline 0.4 and final 1.6, $p<0.001$) as the intervention progressed. While a trend for increased comfort approaching a family member was observed, this was not statistically significant (mean baseline score 1.2 and mean final score 2.2, $p=0.07$).

Donor Evaluation and Transplantation

On behalf of LDC participants, 25 potential donors contacted our center. Of these, 4 had completed evaluation and donated by the end of study and 3 are still completing their evaluation. On behalf of matched controls, there were no donor inquiries or live donor transplants (Table 1C). These outcome differences between LDC participants and matched controls were statistically significant ($p<0.001$). There were 4 deceased donor transplants in the LDC group compared to 5 in the matched control group. There were no deaths in either group.

DISCUSSION

This single-center prospective study focused on training a LDC in order to separate the advocate from the patient and alleviate the barriers associated with identifying a live donor. Despite expressing reticence about approaching potential donors, LDC comfort in approaching others about donation improved throughout the 6-month intervention. More importantly, despite having no potential donors at the time of enrollment, 25 potential donor inquiries were received on behalf of LDC program participants, 4 participants received live donor transplants, and 3 more have donors currently finishing the evaluation process, compared with none among matched controls from our waiting list.

A number of previous studies have attempted to understand and address barriers to identifying a live donor. Multiple cross-sectional surveys and retrospective analyses of live donors have demonstrated that the educational needs of those interested in live donation were not met (17). In a recent cross-sectional study, Waterman et al reported that more than 75% of their kidney recipients felt inappropriately educated about live donation (18). They hypothesized that lack of education may hinder both patients and donors from pursuing live donation. Lunsford et al suggested that education was the best way to attract live donation and dispel myths associated with living donation (19). While a handful of educational programs have been reported, ranging from short instructional videos to an educational question and answer session with transplant staff, many patients still felt ill equipped to pursue live donation and ask others to consider donating (1, 20–22), and interventions of education alone have not been shown to be particularly effective at increasing live donor transplantation rates for participants.

It is important to note that this study is subject to selection bias since enrollment was voluntary. It is plausible that our participants were more motivated and enthusiastic than the wait-list population as a whole. However, no participants had potential live donors at the onset of the study, so motivation alone (assuming there was a difference in motivation between LDC participants and matched controls) had not led them to successfully identifying a live donor prior to participation in the LDC program. In addition, participants had to be able to identify a willing champion, which may limit our sample to those with some social network. But again, the presence of a social network alone (also assuming a difference between participants and matched controls) had not led them to successfully identifying a live donor prior to participation in the LDC program; also, all patients who

expressed an interest in participating in the program were able to easily identify a LDC. While the potential selection bias for this study might affect its generalizability to our entire waiting list, or to other waiting lists, the inferences of the efficacy of this intervention in the particular population that participated are likely robust, with dramatic differences between the LDC participants and matched controls.

In conclusion, approaching and recruiting live donors is a daunting and overwhelming experience for kidney transplant candidates. Current educational modalities or interventions do not adequately meet the needs of patients who would like to pursue and identify live donors. Education alone is not sufficient to decrease the anxiety and fear associated with approaching potential donors. In this trial, LDCs successfully helped increase comfort and decrease concerns associated with approaching a live donor. A dramatic proportion of participants (almost 50%) identified live donors, compared with matched controls for whom no live donors were identified. The live donor champion intervention is inexpensive and can help to decrease wait-list times by increasing the donor pool.

MATERIALS AND METHODS

Study Population

This was a single-center prospective cohort study of 15 adult kidney transplant candidates who had been on the Johns Hopkins KT wait-list for at least 3 months and had no potential live donors at the time of enrollment. A 3-month time period was chosen to exclude recently listed candidates who might be actively approaching potential donors. Each patient was asked to identify a LDC who would attend monthly meetings. Initially, 14/15 (94%) participants were able to identify an LDC. The one participant who was unable to find an LDC was supported by an additional LDC who was identified by an intervention participant who already had an LDC. For each participant, a matched control was identified who was (a) on the waiting list at the beginning of the study, (b) met the inclusion criteria for the study, and (c) was matched on age, gender, race, time on wait-list, blood type, diabetes status, cause of kidney failure and education level using previously reported techniques (15–16). The study was approved by the Johns Hopkins University Institutional Review Board.

Intervention

Based on review of the available literature, clinical judgment, and formative in-depth interviews with wait-listed patients, an intervention was designed. Five session topics were designed (Table 2) to address common barriers associated with identifying a live donor, including (but not limited to) education about kidney failure and live donation, and methods of initiating a conversation about live donation and communication. The intervention occurred over a 6 month time period, throughout which LDCs were provided with educational resources to distribute to potential donors. Additionally, they were given business cards to legitimize and formalize their role and provide them with an additional method of distributing the transplant center contact information.

Outcome Assessment

Participants and matched controls were followed for 9 months after completion of the intervention, with live donor transplantation as the primary outcome of interest. Potential donors calling our transplant center on behalf of a study participant or matched control were tallied. A survey was administered at the beginning and end of each session visit to assess LDC knowledge, perceived barriers to identifying a live donor and comfort with initiating a conversation about live donation (Likert scale from 0=Uncomfortable to 3=Very Comfortable).

Statistical Analysis

Baseline characteristics were compared using t-tests for pseudonormally distributed variables and chi-squared tests for categorical variables. Differences in outcome distribution (donor inquiries, live donor transplantation, donor evaluation, deceased donor transplantation, death on the waiting list, or remaining on the waiting list) between participants in the LDC intervention and their matched controls were assessed using a Fisher's exact test. Increase in comfort was modeled using a linear random effects model with robust standard error estimates to account for multiple observations over time for each individual. Estimates for LDC comfort approaching various subgroups (family, friend, community member, religious group member and stranger) and an overall average comfort score were obtained. All data were analyzed using STATA 11 (StataCorp LP, College Station, TX).

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ABBREVIATION LIST

ESRD	End-stage Renal Disease
DDKT	Deceased Donor Kidney Transplantation
KT	Kidney Transplant
LDC	Live Donor Champion
LDKT	Live Donor Kidney Transplantation

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Figure 1. Champion Comfort Approaching Various Groups About Live Donation Longitudinal responses to the following question: “How comfortable are you, as a live donor champion, at initiating a conversation about live donation and asking a [x] to consider donating a kidney?” (0=Uncomfortable, 1=Slighty Comfortable, 2=Moderately Comfortable, 3=Very Comfortable)

Table 1

Characteristics of LDC-Intervention Transplant Candidates and Matched Controls (A), Characteristics of the Live Donor Champions (B), and Outcomes of Both Cohorts (C).

A.			
	LDC Participants (n=15)	Matched Controls (n=15)	P-Value
Participant Characteristics			
Age at enrollment (Years; Mean)	56.9	55.5	0.7
Wait-list time (Months; Median)	5	8	0.9
Female	10	5	0.07
Race			
Caucasian	7	5	0.5
African American	7	9	
Other	1	1	
ABO			
A	4	4	1.0
B	0	0	
AB	0	0	
O	11	11	
Diabetes	2	2	1.0
Cause of ESRD			
Diabetes	2	2	0.5
Hypertension	4	6	
Polycystic Kidney Disease	3	0	
Glomerulonephritis	4	5	
Other	2	2	
Education			
None	1	0	0.9
High School or GED	4	5	
Technical School	4	5	
College	2	2	
Post-graduate Education	4	3	

B.	
LDC Characteristics	
Age at enrollment (Mean)	52.2
Female	7
Race	
Caucasian	7
African American	7
Other	1
Relationship	

B.	
Spouse	10
Family	3
Friend	2

C.			
Donor Inquiries	25	0	<0.001
Outcomes			
Live Donor Transplantation	4	0	<0.001
Live Donor Evaluation Pending	3	0	
Deceased Donor Transplantation	4	5	
Deaths	0	0	
Wait-listed	4	10	

* Cells represent number of patients unless otherwise specified.

Table 2**Live Donor Champion Educational Intervention: Session Content**

Session	Session Title	Session Details
1	Introduction to Kidney Transplantation and the Live Donor Champion Intervention	<ul style="list-style-type: none"> • Education about kidney failure and live donation • Participant Requirements of LDC Intervention • Intervention Schedule
2	Initiating a Conversation With Potential Live Donors	<ul style="list-style-type: none"> • Conversation Starters • Sample Conversation Material • Role-Playing
3	Spreading the Word	<ul style="list-style-type: none"> • Utilization of media to spread the word on a larger scale including email, internet and local publications • Samples of previously successful campaigns
4	Success Stories: Transplant Recipient and Live Donor Panel	<ul style="list-style-type: none"> • Panel of previous transplant recipients and live donors • Question and answer session
5	Program Recap	<ul style="list-style-type: none"> • Review of previously covered material • Review of participant outcomes