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Addressing Racial Disparities in Live Donor Kidney Transplantation Through Education and Advocacy Training

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Background. The Live Donor Champion (LDC) program trains kidney transplant (KT) candidates and their family/friends ("champions") as educator-advocates for live donor KT (LDKT). This program was created to empower patients and champions, particularly African American (AA) waitlist candidates that historically had lower access to LDKT. We assessed changes in knowledge about and comfort discussing live donation and donor referral associated with LDC participation, both overall and by participant race. **Methods.** We compared 163 adult KT candidates who were LDC participants from October 2013 to May 2016 with 489 matched controls, both overall and by race. We compared changes in comfort and knowledge post-LDC using rank-sum tests among participants by race. We compared time to first live donor referral for participants versus controls, by race, using Cox regression. **Results.** Post-LDC versus pre-LDC, participants had higher median knowledge (83% versus 63% on 12-question quiz; $P<0.001$) and comfort (1.8 versus 1 on 4-point Likert scale; $P<0.001$). Among participants, AAs had similar baseline and final knowledge ($P=0.9$ and $P=0.1$, respectively) and baseline comfort ($P>0.9$) as non-AAs but higher final comfort (2 versus 1.4; $P=0.005$) than non-AAs. LDC participants were 5.8 times as likely as controls to have a live donor referral (aHR $_{3.76}5.78_{8.89}$; $P<0.001$); the impact of LDC participation was similar among non-AAs and AAs (p-interaction = 0.6). **Conclusions.** The LDC program increased knowledge, comfort, and live donor referral for non-AA and AA participants, underscoring the effectiveness in the program in promoting LDKT in a population with historically lower access to LDKT.

(*Transplantation Direct* 2020;6: e593; doi: 10.1097/TXD.0000000000001041. Published online 12 August, 2020.)

INTRODUCTION

Living donor kidney transplantation (LDKT) has received increased attention within the transplant community as a method for increasing access to kidney transplantation (KT) for waitlist candidates, particularly since 1 in 4 Americans report that they would be willing to donate a kidney to a friend or family member in need.[1] However, the number of LDKTs performed in the United States has decreased substantially since 2004.[2] This has been attributed to increases in medical unsuitability, financial disincentives, and in adequate education and outreach, among other reasons.[3,4] The low rate of LDKT has disproportionately affected African American (AA) KT candidates[3]; only 13.8% of LDKT recipients are AA,[5] though AAs comprise 29% of the KT waitlist population.[6] Though national deceased donor organ allocation policies have helped to reduce disparities in transplant access by race,[7] disparities in access to LDKT, which provides the best KT outcomes,

Received 27 March 2020. Revision received 16 June 2020.

Accepted 18 June 2020.

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This work was supported by NIDDK (grant K24DK101828 and R01DK111966), NIA (grant F32AG044994), AHRQ (grant K01HS024600), HRSA (grant R39OT31103), and Doris Duke Charitable Foundation Clinical Research Mentorship grant (Segev/Ruck).

The authors declare no conflicts of interest.

E.A.K. participated in study design, data analysis and interpretation, drafting article, and revising article. J.M.R. participated in data analysis and interpretation, drafting article, and revising article. J.G.-W. participated in study design, data interpretation, and revising article. M.G.B. participated in study design, data analysis and interpretation, and revising article. K.K. participated in study design, data analysis and interpretation, and revising article. T.P. participated in study design, data interpretation, and revising article. A.C. participated in study design, data interpretation, and revising article. D.L.S participated in study design, data interpretation, and revising article.

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ISSN: 2373-8731

DOI: 10.1097/TXD.0000000000001041

might be worsening: Purnell et al found that AAs had 65% lower access than whites from 1995 to 1999 and 73% lower access from 2010 to 2014.[8] Furthermore, our group found that racial disparities in access to LDKT existed at every transplant center in the United States,[9] underscoring that addressing disparities in and improving overall access to LDKT will require novel programs that address barriers to LDKT.

Known barriers to identifying a live donor include lack of timely and comprehensive education about living donation,[10] reluctance to discuss one's illness, and hesitance or discomfort approaching others about live donation.[10–17] However, many candidates have friends and family members who are eager to help,[18] even if they are unable to donate themselves. Our center has developed a novel intervention to empower friends and family to address barriers to identifying a live donor for a KT candidate. The Live Donor Champion (LDC) program is an education and advocacy training program for KT candidates and their champions, who are friends or family members willing to learn about live donation, spread awareness, and help the candidate identify potential live donors. In a pilot study of 15 LDC participants, 7 potential donors were referred for participants compared with zero for matched controls on the waitlist.[19] Though the results of that study were encouraging, the sample size of 15 participants limited its generalizability and our ability to analyze the association between program participation and attaining live donor referral in particular subpopulations, such as AA KT candidates for whom barriers seem to be the most challenging. Therefore, we decided to examine the result of LDC participation at our center for a larger sample of adult KT candidates.

Using data from all LDC participants at our center between October 2013 and May 2016, we sought to quantify the change in knowledge of live donation and comfort initiating conversations about live donation associated with participation in the LDC program, compare the time to first live donor referral for LDC participants versus matched controls, and determine whether the association between LDC program participation and these outcomes differed by transplant candidate race.

MATERIALS AND METHODS

Study Population

We studied all participants in the LDC program between October 2013 and May 2016. During this time period, all patients on the KT waitlist at our institution were eligible to participate in the LDC program and were contacted via telephone about participating. During this time period, the waitlist had approximately 1000 candidates at any given time, of which approximately 46% were AA. Overall, 163 KT candidates participated, 140 were instructed to bring a friend or family member to serve as their champion, and 111 (79%) found a champion that attended at least 1 meeting. Of the 122 candidates that participated with a champion, we have survey data from 80 champions. For each candidate who participated in the LDC program, we used 1:3 iterative expanding radius matching, as previously described,[20] to identify matched controls who (a) had been on the waitlist for the same amount of time as the candidate, and (b) shared candidate characteristics of age, sex, race, and blood type (Figure 1). Demographic and clinical characteristics were ascertained from electronic medical records. This study was approved by the Johns Hopkins University Institutional Review Board.

Live Donor Champion Program

The LDC program was designed based on review of the available literature, clinical judgment, and formative in-depth interviews with waitlisted patients with the intention to help waitlist candidates identify a live donor through education and with the aid of an additional person, or "champion." The intervention was conducted as previously described,[19] except that the session with a panel of transplant surgeons and nephrologists was discontinued based on participant feedback that this was the least important session. Participants also desired a more condensed program, so this session was discontinued. Therefore, the participants in the LDC described in this study participated in 5 sessions, each approximately 2 hours in length, held once a month at our transplant center (Table 1). Candidate and champions attended sessions together. Each session was led by a transplant physician or clinical coordinator. LDC sessions incorporated formal didactics, active-participant learning, personal stories, moderated group discussions, role-playing, and other skill-building exercises. Participants debriefed after each session in a "support group" atmosphere. The LDC program is a supplement to standard of care, which includes an educational pamphlet and discussions with transplant providers about the evaluation process, waitlist status (listed versus inactive versus removed), transplantation risks and benefits, high kidney donor profile index and donation after cardiac death donors, living donor options including incompatible transplants, transplant surgery, what to expect posttransplant, the importance of medication compliance, the importance of social support, and financial aspects of transplantation.

Outcome Assessment

To assess knowledge about live donation, we developed a 12-question multiple-choice quiz (Supplemental Materials, SDC, http://links.lww.com/TXD/A269). Questions were drawn from the educational material used in the LDC program sessions. The quiz was reviewed by transplant nephrologists, coordinators, and surgeons involved in the LDC program design and administration. The knowledge quiz was administered before starting the LDC program and again after completion of the program. Therefore, measurements of knowledge were taken several weeks apart, rather than immediately before and after particular instruction, to better assess knowledge that was retained by participants. Before beginning the program and at every session, we also assessed comfort initiating conversations about live donation using a 4-point Likert scale (0 = uncomfortable to 3 = very comfortable).

We also recorded the time at which a participant or control received their first live donor referral (point in time at which a potential live donor contacts our center and initiates the donor evaluation process). Time to referral was calculated from entry into the LDC program for participants and from a similar point in time (ie, after a similar amount of time on the waitlist) for matched controls. Live donor referral was selected as the outcome of interest because the LDC program was designed to address transplant candidates' difficulties talking about live donation and approaching potential live donors. Donor referral is the most immediate outcome on the pathway to live donor transplantation and is the outcome that best measures the effect of the LDC program. Potential

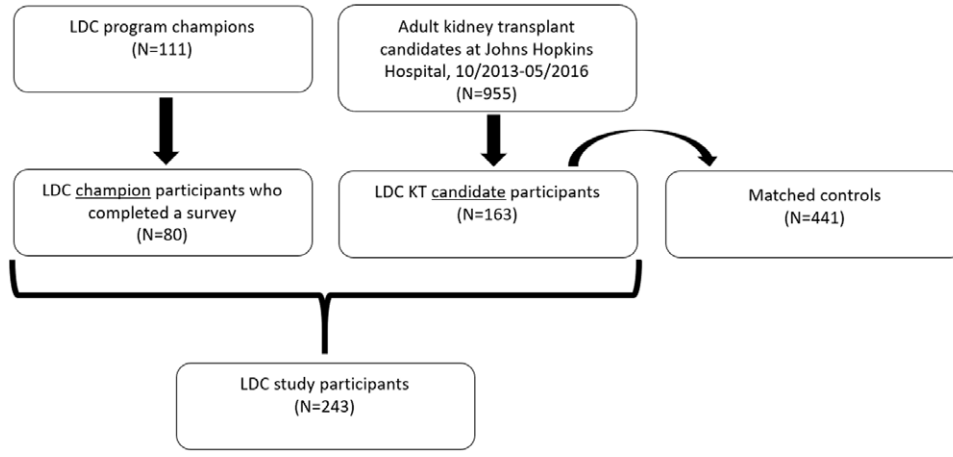

FIGURE 1. Living donor champion program recruitment. KT, kidney transplant; LDC, Live Donor Champion.

TABLE 1.

Description of live donor champion program sessions

Session	Session title	Session content
1	Introduction to kidney transplantation and the live donor champion program	Program leaders provided education about kidney failure, kidney transplantation, and live donation with a focus on the risks of live donation, benefits to recipient, and recovery following live donation.
2	Initiating a conversation with potential live donors	Program leaders provided an introduction to effective communication skills and sample language to use during conversations about live donation. Participants also role-played and practiced using supplemental materials (eg, educational pamphlets and business cards) as conversational aids.
3	Spreading the word	Participants brainstormed a list of contacts in their personal networks beyond friends and family. Candidates wrote a short script about their search for a live donor, which could be used when talking one-on-one with potential donor, when speaking in front of large groups, or when creating posts or emails for online communications.
4	Success stories: transplant recipient and live donor panel	Participants were able to ask questions of prior donors and recipients. Participants were encouraged to invite potential donors to attend this session.
5	Program recap	Program leaders highlighted the knowledge and skills gained by participants and facilitated a discussion of challenges to identifying a live donor and the next steps in that process.

donors are ruled out for many different reasons during the evaluation progress, many of which would have nothing to do with the LDC program. Therefore, we determined that live donor referral was the most appropriate measure of LDC program success.

Statistical Analysis

We estimated the changes in knowledge about live donation and comfort initiating conversations about live donation using Wilcoxon signed-rank tests. We estimated the differences in the magnitude of change between participant groups (candidates participating alone versus candidates participating with a champion versus champions) and between racial groups (among transplant candidates, non-AA, versus AA) using Kruskal-Wallis tests. Kaplan-Meier curves and a Cox proportional hazard model were used to compare the time to first donor referral among participants and controls, with censoring for deceased donor transplantation, live donor transplantation from a donor identified before starting the LDC program, death, and administrative censoring at the end of follow-up. Robust variance was used to account for clustering of controls. For participants, the association between baseline characteristics and donor referral was estimated using t-tests for pseudonormally distributed continuous variables and Chi-squared tests for categorical variables. Confidence intervals are reported as per the methods of Louis and Zeger.[21] All data were analyzed using Stata 14 (StataCorp LP, College Station, TX).

RESULTS

Study Population

Among 163 kidney candidates who participated in the LDC program, the median age was 58 (interquartile ratio [IQR], 45–65) years, 49.7% were female, 50.3% were AA, and 53.6% had blood type O (Table 2). The median time spent on the waitlist by candidate participants before LDC enrollment was 9 (IQR, 4–17) months. There were no significant differences in age, sex, race, blood type, or months without a live donor referral since listing between KT waitlist candidates who participated in LDC and the 441 KT waitlist candidate controls or between participants and all other transplant candidates on the waitlist at our center during the same time period (Table 2). There were also no differences in age, sex, blood type, or months without a live donor referral between the 122 candidate participants who had a champion and the 41 LDC candidate participants who participated alone; however, candidates who participated alone were more likely to be AA (68.3% versus 44.3%; $P = 0.008$) (Table 3).

TABLE 2.

Characteristics of live donor champion participants vs matched controls

Characteristic	LDC (N = 163)	Controls (N = 441)	P
Age, median (IQR)	58 (45–65)	58 (46–65)	0.6
Female	49.7%	49.5%	0.9
African American	50.3%	52.3%	0.7
Blood type			0.4
O	53.1%	57.3%	
A	25.3%	23.3%	
B	16.1%	16.7%	
AB	5.6%	2.7%	
Mo since listing without a donor referral, median (IQR)	9 (4–17)	9 (4–17)	0.9
Time to referral after participation, median (IQR)	9 (3–21)	N/A[a]	

[a]As controls did not participate in LDC, there was no similar "start date" for the time to referral after participation comparison.
IQR, interquartile ratio; LDC, Live Donor Champion.

TABLE 3.

Characteristics of live donor champion participants who participated with a champion vs alone

Characteristic	Participated with a champion (N = 122)	Participated alone (N = 41)	P
Age, median (IQR)	59 (44–65)	56 (46–65)	0.7
Female	53.3%	39.0%	0.1
African American	44.3%	68.3%	0.008
Blood type			0.9
O	52.9%	53.7%	
A	26.5%	22.0%	
B	14.9%	19.5%	
AB	5.8%	4.9%	0.3
Mo since listing without a donor referral, median (IQR)	8 (4–15)	10 (4–21)	

IQR, interquartile ratio.

Knowledge About Live Donation

Among all study participants who completed both knowledge questionnaires ($N = 54$), median baseline knowledge score was 63% (IQR, 50%–75%) and median final knowledge score was 83% (IQR, 67%–90%), a statistically significant increase ($P < 0.001$). The knowledge of candidates participating alone who completed both knowledge questionnaires (N = 9) increased from a baseline of 50% (IQR, 50%–70%) to a median final score of 83% (IQR 80%–90%) ($P = 0.007$), ^^^^and the knowledge of candidates participating with a champion who completed both knowledge questionnaires ($N = 22$) increased from a median baseline score of 63% (IQR, 58%–75%) to a median final score of 82% (67%–92%) ($P = 0.001$). Finally, the knowledge of champions who completed both knowledge questionnaires (N = 23) increased from a median baseline score of 67% (IQR, 50%–83%) to a median final score of 80% (67%–90%) ($P = 0.002$). There were no statistically significant differences between the 3 groups in terms of median knowledge scores at baseline ($P = 0.4$) and on final assessment ($P = 0.7$), or change in knowledge score ($P = 0.1$) (Figure 2A).

Among non-AA candidates who completed both knowledge questionnaires (N = 13), there was a statistically significant increase in median knowledge from a baseline of 60% (IQR, 50%–70%) to a final score of 90% (IQR, 83%–90%) ($P = 0.001$). AAs who completed both knowledge questionnaires (N = 18) similarly experienced an increase in median knowledge, from a baseline of 63% (IQR, 50%–75%) to a final score of 80% (IQR, 67%–90%) ($P = 0.004$; Figure 3). Non-AA and AA candidates had similar knowledge at baseline ($P = 0.9$) and on final assessment ($P = 0.1$) and experienced similar increases in knowledge between the 2 time points ($P = 0.3$; Figure 2B).

Comfort Initiating Conversations About Live Donation

Among all study participants who completed both comfort questionnaires (N = 196), median baseline comfort with initiating conversations about live donation was 1.0 (IQR, 0.4–2.0) and median final comfort was 1.8 (IQR, 1.0–2.4), a statistically significant increase ($P < 0.001$). Candidates participating alone who completed both comfort questionnaires (N = 28) experienced a statistically significant increase in median comfort from 0.5 (IQR, 0.1–1.1) at baseline to 2.0 (IQR, 1.3–2.5) on final assessment ($P < 0.001$). Similarly, candidates participating with a champion who completed both comfort questionnaires (N = 88) increased their knowledge from a median of 1.0 (IQR, 0.4–2.0) at baseline to a final median score of 1.8 (IQR, 1.0–2.4; $P < 0.001$). Champions who completed both comfort questionnaires (N = 80) increased their comfort from a median of 1.4 (0.6–2.1) at baseline to 1.8 (1.2–2.5) on the final assessment ($P < 0.001$). Among these groups, candidates who participated alone had a statistically significantly lower baseline comfort than candidates participating with a champion ($P = 0.04$) and than champions ($P < 0.001$). However, all groups had a similar final comfort level ($P = 0.7$; Figure 3A).

Among non-AA candidates who completed both comfort questionnaires (N = 59), median baseline comfort increased statistically significantly ($P < 0.001$) from a baseline of 0.8 (IQR, 0.4–1.6) to a final comfort of 1.4 (IQR, 1.0–2.0). AA candidates who completed both comfort questionnaires (N = 56) also experienced a statistically significant increase ($P < 0.001$) in median comfort from a baseline of 1.0 (IQR, 0.3–1.9) to a final comfort of 2.0 (IQR, 1.5–2.6; Figure 3). The increase in comfort was greater for AA candidates compared with non-AA candidates ($P = 0.049$), and the final comfort score was statistically significantly higher for AA candidates versus non-AA candidates ($P = 0.005$; Figure 3B).

Participants who experienced an increase in their comfort with living kidney donation had significantly higher final knowledge scores (median 90 [IQR, 80–92] versus 66 [54–79]; $P = 0.009$) despite similar baseline knowledge scores (63 [50–75] versus 58 [41–75]; $P = 0.5$).

Donor Referrals

We received 81 live donor referrals on behalf of 39 LDC candidate participants. KT candidates who participated in the LDC program were almost 5.8 times as likely as matched controls to have a donor referral (aHR $_{3.76}5.78_{8.89}$; $P < 0.001$; Figure 4). Median (interquartile range, IQR) time from entry to first donor referral was 11.1 months (IQR, 3.1–31.8 mo) overall. Among LDC participants, the median time to referral was 9.1 (IQR, 3.3–20.8) months. Among candidates who participated in the LDC program, we observed similar likelihood

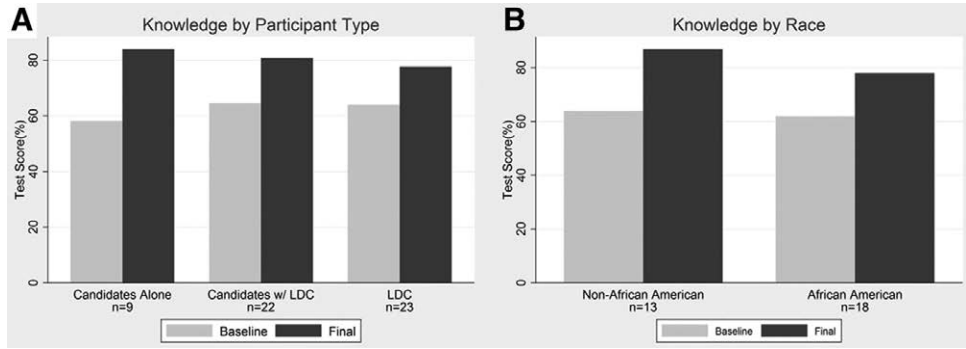

FIGURE 2. Knowledge about live donation at baseline and after participation in the live donor champion program (A) by participant type and (B) by race. LDC, Live Donor Champion.

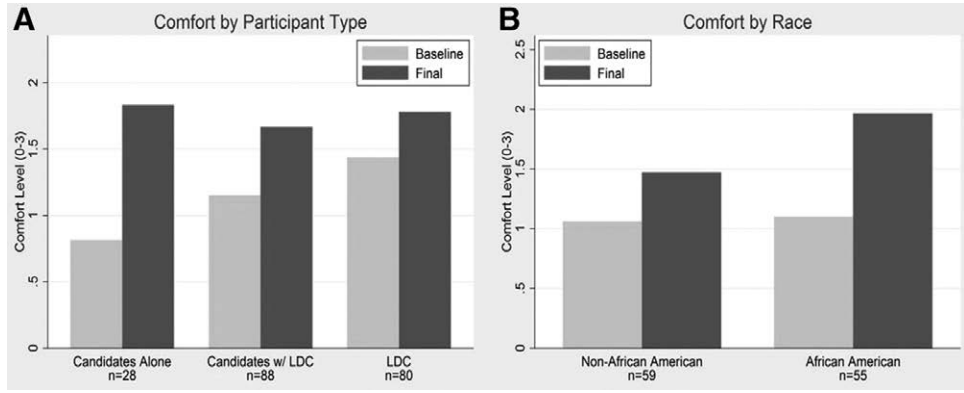

FIGURE 3. Comfort initiating conversations about live donation at baseline and after participation in the live donor champion program (A) by participant type and (B) by participant race. Comfort was assessed using a 4-point Likert scale ranging from 0 (uncomfortable) to 3 (very comfortable). LDC, Live Donor Champion.

of having a live donor referral among candidates participating with a champion and candidates participating alone (aHR $_{0.69}1.46_{3.13}$; $P = 0.3$).

Among non-AAs, candidate participants were 6 times as likely as controls to have a donor referral (aHR $_{3.31}5.96_{10.7}$; $P < 0.001$). Among AAs, candidate participants were 5.6 times as likely to have a donor referral (aHR $_{2.95}5.62_{10.69}$; $P < 0.001$; Figure 5). Participation in the LDC program was associated with a similar magnitude of increase in likelihood of donor referral compared with controls among non-AAs and AAs (interaction aHR $_{0.36}0.80_{1.81}$; $P = 0.6$).

Donors who received live donor referrals and those who did not receive live donor referrals has similar baseline comfort with living kidney donation (0.6 versus 0.4; $P = 0.9$). However, donors who received a referral had significantly higher final comfort with living donation (2.4 versus 1.8; $P = 0.03$) and significantly greater increase in comfort level (1.8 versus 1.0; $P = 0.01$).

DISCUSSION

In this single-center study, participation in the LDC program increased the knowledge, comfort, and donor referral rates of KT candidates, regardless of race. Compared with matched controls, candidates participating in the LDC program were 5.8 times as likely to have a live donor referral. The increase in likelihood of live donor referral was similar among waitlist candidates participating in the LDC program with and without a champion. Similarly, participation in the LDC program was associated with a 5- to 6-fold higher likelihood of live donor referral compared with controls among both non-AAs and AAs.

Our finding that participation in the LDC program increased comfort initiating conversations about live donation is consistent with data from our initial pilot study of 15 patients, which showed an increase in comfort over time for both candidates and their champions.[19] However, the larger sample size in our current study was more generalizable and allowed analysis of subpopulations, such as candidates of different racial backgrounds and those who participated without a champion. While non-AA and AA participants had similar baseline comfort initiating conversations about live donation before participation in the LDC program and both groups experienced significant increases in their reported comfort, AA participants experienced greater gains and had a significantly higher final comfort score. Additionally, compared with candidates who participated with a champion, candidates who participated alone had lower baseline comfort with and knowledge about donation but experienced a larger increase in both comfort and knowledge, resulting in similar final comfort and knowledge levels. Candidates who participated alone also had similar rates of donor referral to candidates who participated with a champion. Therefore, the education provided through the LDC program might enable candidates to serve as their own champion. This suggests that the LDC program is effective in improving the live donation-related knowledge of candidates and their champions, that education is an effective tool for empowering candidates and their champions, and that with sufficient education many candidates can serve as

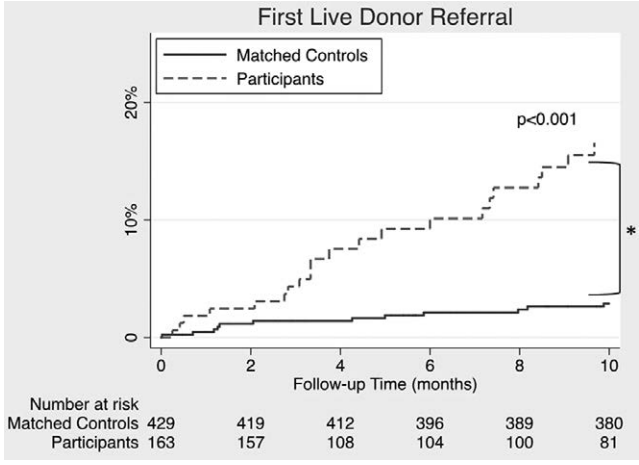

FIGURE 4. Time to first live donor referral among waitlist candidates participating in the live donor champion vs matched controls. LDC participants were 5.2 times as likely as matched controls to receive a live donor referral. LDC, Live Donor Champion.

their own champions. For this reason, the education received by recipients through the LDC intervention was regarded as a benefit and mediator of any observed effects rather than as a confounder. Based on these findings, LDC could serve as a template for effective donor education and empowerment even at centers that do not dedicate resources to helping donors identify a champion. Therefore, candidates who are unable to find a champion should be encouraged to participate, and education should remain a focus of transplant programs due to its proven effectiveness in helping transplant candidates identify donor candidates.

As in our pilot study, participation in the LDC program was associated with an increased likelihood of live donor referral for KT candidates. This outcome was specifically chosen to isolate the effect of the LDC program on recipient's ability to identify a donor, as numerous other factors (eg, health eligibility, financial burden of donating) affect potential donors' progression through the evaluation process. While not all transplant candidates were able to find potential donors

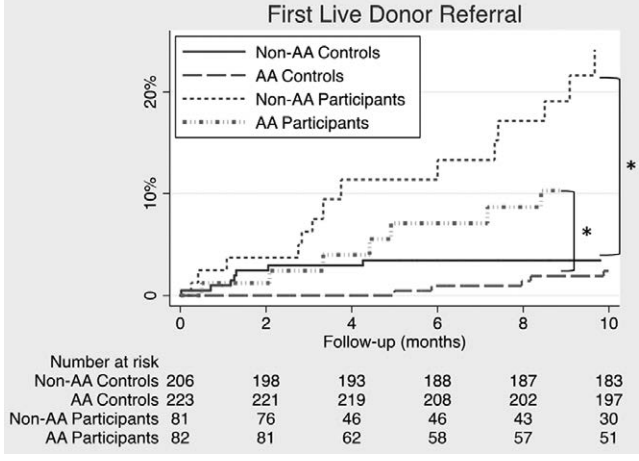

FIGURE 5. Time to first live donor referral among waitlist candidates participating in the live donor champion program vs matched controls, by candidate race. African American LDC participant candidates were 56% less likely than non-African American LDC participant candidates to have a live donor referral. AA, African American; LDC, Live Donor Champion.

through the LDC program, it helped 1 quarter of candidates with no existing donor referrals (and for whom usual care had failed) reach this important milestone. Overall, candidate participants had almost 6 times the likelihood of a donor referral compared with matched controls. Additionally, participation in the LDC program was associated with a similar increase in likelihood of live donor referral among AA and non-AA LDC participants. Our findings suggest that the LDC program is effective in increasing live donor referral for AA waitlist candidates, a population that receives a disproportionately low percentage of LDKTs. Previously, several other interventions designed to increase access to LDKT for AA waitlist candidates have been tested, such as the "House Calls" initiative by Rodrigue et al[16,22–24] and the Talking About Live Kidney Donation (TALK) study by Boulware et al.[25] In the "House Calls" study, home-based education dramatically improved live donor referral rates for both black and white participants but racial disparities in access to LDKT remained: among participants who received home-based education, white participants were more likely to have a live donor inquiry (87.5% versus 77.4%), a potential live donor get evaluated (71.9% versus 48.4%), and receive a LDKT (59.4% versus 45.2%).[24] However, the House Calls study unquestionably demonstrated the power of patient-centered supplemental education in improving access to LDKT. The persistence of racial disparities suggests that multiple strategies for improving access to LDKT might be needed. Our study builds upon this existing literature of patient-centered education and empowerment by demonstrating a novel program that improved knowledge and comfort for AA and non-AA participants and increased living donor referrals rates for both AA and non-AA participants who had struggled to find potential donors. For these reasons, we believe that the LDC program is superior to standard of care and offers benefit to participants, particularly those who have otherwise failed to identify potential living donor candidates.

Notable limitations to this study include a small sample size within a single institution, a non-randomized design, and potential for selection bias. Participant enrollment was voluntary, and it is possible that participants were more motivated to identify a live donor than other candidates on the waitlist. Additionally, participants who attended LDC program sessions but did not complete the surveys could similarly be less motivated. Since knowledge and comfort surveys were administered at specific meetings, any donors and Champions who were absent from that particular meeting but participated in the remainder of the program were unable to complete these assessment tools, which limited our ability to evaluate changes in knowledge and comfort for all participants. The observed increases in donor knowledge, comfort, and live donor referral might be partially due to increased access to transplant center staff rather than solely due to the educational materials, but we believe that this is an inherent component of the program. While we found that participation in the LDC program resulted in similar increases in likelihood of donor referral among AA and non-AA participants, it is possible that this result is due to a lack of statistical power.

CONCLUSION

In conclusion, low rates of LDKT and racial disparities in access to LDKT might be reduced through targeted

educational programs and the involvement of candidates' friends and family members as champions. The LDC program has demonstrated effectiveness for waitlist candidates regardless of race and might decrease disparities in access to LDKT by engaging AAs in this program.

ACKNOWLEDGMENTS

This work was supported by grant number K24DK101828 and R01DK111966 from the National Institute of Diabetes and Digestive and Kidney Diseases, grant number K01HS024600 from the Agency for Healthcare Research and Quality, and by grant number R39OT31103 from the Health Resources and Services Administration. The analyses described here are the responsibility of the authors alone and do not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the US Government. Elizabeth King was supported by National Institute on Aging grant F32AG044994, a Ruth L. Kirschstein National Research Service Award. Jessica Ruck and Dorry Segev are supported by a Doris Duke Charitable Foundation Clinical Research Mentorship grant.

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