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Making House Calls Increases Living Donor Inquiries and Evaluations for Blacks on the Kidney Transplant Waiting List

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Abstract

Background—Blacks receive live donor kidney transplantation (LDKT) less often than patients of all other races. We evaluated the effectiveness of educational interventions in removing barriers to LDKT for blacks.

Methods—Patients were randomized to three interventions in which health educator(s) delivered an intervention to (a) the patient and his/her guests in the patient's home (House Calls, HC n=54), (b) clusters of patients and their guests in the transplant center (Group-Based, GB n=49), (c) the individual patient alone in the transplant center (Individual Counseling, IC n=49).

Results—At the 2-year endpoint, 15% (8), 8% (4), and 6% (3) of HC, GB, and IC patients, respectively, received LDKT ($p=0.30$). HC patients were more likely than GB and IC patients to have at least one donor inquiry (82% vs. 61% vs. 47%, $p=0.001$) and evaluation (65% vs. 39% vs. 27%, $p<0.001$). HC patients also were more likely to have higher knowledge, fewer concerns, and higher willingness to talk to others about donation 6 weeks post- intervention.

Conclusions—These findings underscore the importance of including the patient's social network in LDKT education and the potential of the HC intervention to reduce racial disparity in LDKT rates.

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The authors have no conflicts of interests to disclose. Dr. Egbuna was a faculty member and transplant nephrologist at Beth Israel Deaconess Medical Center and Harvard Medical School during the development and initial implementation of the study. He is now employed as Clinical Research Medical Director for Amgen Inc., although Amgen has not been involved in any way with the study reported in this manuscript.

Keywords

live donor kidney transplantation; kidney transplantation; living donation; kidney donation; living donor; psychosocial; transplant education; race

INTRODUCTION

Racial inequities in live donor kidney transplantation (LDKT) persist. For instance, in the past decade, the percentage of kidney transplants from living donation (LD) for blacks was 15%, which is considerably lower than LDKT rates for whites (47%), Hispanics (31%), Asians (29%), and other races (27%) (based on OPTN data, www.optn.transplant.hrs.gov, accessed October 19, 2013). Lower LDKT and LD rates for blacks may be explained, in part, by a higher prevalence of conditions (e.g., diabetes, hypertension, obesity) precluding donation, higher likelihood of ABO incompatibility, heightened concerns about pursuing LDKT, difficulties initiating donation discussions with others, and differences in social networks based on race.[1-11] Also, systems factors may also interfere with the pursuit of LDKT among black patients. Typical clinic-based education, for instance, is time-limited, excludes the patient's social support system, often is not culturally tailored, requires a high level of health literacy and numeracy, and does not model the behavioral skills necessary to facilitate donation discussions with others.[7,12]

We developed a House Calls (HC) intervention to directly engage the patient's social network in LDKT education.[12,13] HC involves a single 60-90 minute session delivered by health educators in the patient's home, with invited members of the patient's social network. Findings from our first RCT showed that HC yielded more LD inquiries, evaluations, and transplants compared to standard clinic-based transplant education, [13] with notably more robust effects of HC for black patients.[14] Considering the potential of HC to reduce disparity in LDKT access, we sought to expand its evaluation in a larger cohort of black patients and to compare it to similarly intensive individual counseling (IC) and group-based (GB) education implemented in the transplant center.[12] We hypothesized that HC patients would be more likely than other patients to receive LDKT (primary outcome), have donor inquiries and evaluations, and have higher LDKT readiness, more willingness to talk to others about donation, and fewer concerns about LDKT (secondary outcomes).

RESULTS

Patient Enrollment, Retention, and Characteristics

We identified 213 black potential study patients during the enrollment period, of which 186 were approached, 164 were consented, 152 were randomized, and 145 received the allocated intervention. (Figure 1). Twelve patients consented but did not complete the baseline assessment. Participants were significantly younger than non-participants ($p=0.02$). In all, 87% and 89% completed the 1 and 6 week follow-up questionnaires, respectively. The 2-year endpoint was unknown for 3 patients, who transferred care to other centers and the final outcome could not be verified. The intervention groups did not differ significantly on sociodemographic or clinical characteristics (Table 1).

Intervention Characteristics and Satisfaction

Intervention duration was similar across groups (HC: 78.3 min, GB: 78.7 min, IC: 77.6 min, $p=0.93$). Patient (HC: 4.6, GB: 4.2, IC: 4.3, $p=0.67$) and guest (HC: 4.7, GB: 4.5, $p=0.89$) satisfaction ratings were high and did not vary by group. There was no difference in health educator discussion of the *a priori* educational topics (HC: 1,097/1,122 = 98%; GB: 994/1,034 = 96%; IC: 1,002/1,034 = 97%; $p=0.09$). On average, the HC group had more guests in attendance (mean: 7.9, range: 2 to 24, total: 419) than the GB group (mean: 2.3, range: 0 to 10, total: 107) ($p < 0.001$).

LDKT

Forty-one (27%) patients received either LDKT ($n=15$) or deceased donor kidney transplantation (DDKT, $n=26$) within 2 years of intervention (Table 2). The LDKT rate among the subset of patients who received a transplant ($n=41$) was 42% (HC), 31% (GB), and 33% (IC) ($p=0.79$). The LDKT rate among all study patients ($n=152$) was 15% (HC), 8% (GB), and 6% (IC) ($p=0.30$). There was no group effect for time to LDKT ($p=0.72$).

LD Inquiries and Evaluations

HC patients were more likely than GB or IC patients to have at least 1 donor inquiry (82% vs. 61% vs. 47%, $p=0.001$) and evaluation (65% vs. 39% vs. 27%, $p<0.001$). GB and IC groups did not differ significantly ($p=0.16$ and $p=0.19$, respectively). HC patients had more donor inquiries (total=164, mean=3.04, range=0-15) and evaluations (total=100, mean=1.85, range=0-8) than GB patients (inquiries: total=80, mean=1.63, range=0-9; evaluations: total=48, mean=0.98, range=0 to 8) and IC patients (inquiries: total=39, mean=0.80, range=0-5; evaluations: total=17, mean=0.35, range=0-3) ($p<0.001$ and $p<0.001$, respectively).

LDKT Readiness Stage, Knowledge, Concerns, and Willingness to Talk to Others (Table 3)

Group did not differ in LDKT readiness stage, knowledge, concerns, or willingness to talk to others prior to randomization (P values > 0.05).

Pre-intervention, most patients (60%) self-classified as being in the Pre-Contemplation or Contemplation LDKT readiness stage. However, 6 weeks post-intervention, more HC (72%) than GB (34%) and IC (14%) patients were in the Action or Maintenance stage ($p<0.001$). More GB than IC patients were in these latter LDKT readiness stages ($p=0.02$).

From pre-intervention to 1 week post-intervention, all groups showed an increase in LDKT knowledge, a reduction in LDKT concerns, and an increase in willingness to discuss donation with others (P values < 0.05). HC patients had higher knowledge scores than GB and IC patients at 1 ($p=0.004$ and $p<0.001$, respectively) and 6 week ($p<0.001$ and $p<0.001$, respectively) post-intervention. GB patients had higher knowledge scores than IC patients at 1 week post-intervention ($p=0.002$). HC patients had fewer concerns than IC patients at 1 week post-intervention ($p=0.001$), and fewer concerns than GB ($p=0.04$) and IC ($p<0.001$) patients at 6 weeks post-intervention. GB patients had fewer concerns than IC patients at 6 weeks post-intervention ($p=0.02$). Finally, willingness was higher for HC than for IC patients at 1 week post-intervention ($p<0.001$), although willingness did not differ for HC

and GB patients ($p=0.10$). At 6 weeks post-intervention, HC patients had higher willingness than GB ($p<0.001$) and IC ($p<0.001$) patients, and GB patients had higher willingness than IC patients ($p=0.004$).

DISCUSSION

In the United States, the historical LDKT rate for blacks is substantially lower than that for patients of all other races or ethnicities. This racial disparity is further exacerbated by the recent decline in living donation rates, which has disproportionately impacted blacks.[15] Numerous barriers to LDKT for blacks have been identified,[5,6,9,16] yet few specific interventions are designed to attenuate the LDKT decline in this population. In the current study, HC – and, to a lesser extent, the GB intervention – was successful in engaging the patient’s social network to facilitate more LD inquiries and evaluations, as well as improvements in LDKT knowledge and concerns, willingness to talk to others about LD, and readiness to pursue LDKT. Both HC and GB interventions yielded LDKT rates that exceed the expected LDKT rate for black wait-listed patients at our center. There was a trend toward a greater proportion of HC (15%) patients than GB (8%) or IC (6%) patients receiving LDKT by the 2 year endpoint, but this difference did not reach statistical significance.

Engagement of the patient’s support system in the LDKT educational process was very well received and appears to have several specific benefits for the transplant candidate. Patients and guests in the HC and GB groups reported high satisfaction with the intervention. Many commented that such education should be mandatory and include the patient’s social network. Education that includes the support system also may help the patient crystalize and consolidate LDKT information, which can be overwhelming and complex. Moreover, it likely accelerates LDKT discussions with others and alleviates many of their concerns about LDKT, thus increasing willingness to talk with others about LD and advancing their stage of LDKT readiness. In contrast, educating the patient alone relies on them to initiate the LD dialogue with family members and friends who are likely not as informed about transplantation and donation. Also, IC patients do not benefit from hearing directly about the issues that are important to others in their social network, which may explain why they continued to have more LDKT concerns than HC and GB patients.

All three interventions improved LDKT knowledge, reduced LDKT concerns, and increased willingness to talk to others about LD. Transplant programs focused on these specific outcomes may opt for IC as a more cost-effective and efficient option. However, unlike IC patients, HC and GB patients showed more robust changes in LDKT concerns and willingness over time, which may be attributed to having more LDKT interactions with people in their social networks after the intervention. Interestingly, GB patients were more likely than all others to have discussions with other transplant patients following the intervention (data not reported), which may be one of the benefits of bringing groups of patients together with their respective social networks.

While the GB intervention may provide a cost-effective alternative by educating the patient and his/her social network in the transplant center, HC reached nearly 4 times more potential

donors, triggered more patients to discuss donation with family and friends, led to more LD inquiries and evaluations, and led to greater changes in LDKT readiness stage, knowledge, concerns, and willingness 6 weeks post-intervention. These outcomes are critical precursors to successful LDKT for many patients [17] and they mirror those found in our previous evaluation of HC.[13,14] Also, educating more people in the patient's social network likely contributed to more informed decision-making by potential donors who participated in the intervention, although this warrants evaluation in subsequent HC studies. Indeed, only a small percentage of adults who initiated LD evaluation completed donation, which is not uncommon among black potential donors and highlights both the need to better educate the support system about eligibility criteria and the need to generate more potential donors to achieve the desired LDKT outcome. Unfortunately, in the current study we did not record the reason potential donors dropped off the pathway.

Importantly, the robust effects on secondary outcomes notwithstanding, HC did not yield statistically higher LDKT rates than the other interventions. While there was a trend toward more LDKTs for HC patients, the lack of significant effect may be due to insufficient power. We powered the study based on an expected enrollment of 180 patients, but we fell short of this target by 16% due to insufficient numbers of black patients at our center. Considering the racial disparity in LDKT, however, it is important to acknowledge that the observed LDKT rates in the HC (15%) and GB (8%) groups were higher than the LDKT rates for black patients added to the waiting list at our center (4%) and nationally (2%) in the past decade. Indeed, the 15% LDKT rate observed for the HC patients in this study is comparable to the observed LDKT for white patients added to the waiting list at our center (13%) and nationally (10%) in the past decade, thus showing potential to close this racial disparity gap.

While not statistically significant, more HC (n=11, 20%) than IC (n=6, 12%) patients received a deceased donor transplant during the study's observation period, which may have contributed to the statistically insignificant LDKT finding. In our post hoc review of these deceased donor cases, 36% (4/11) of HC patients who received deceased donor transplants had potential LDs who were still being evaluated for donation eligibility. In comparison, only 17% (1/6) of the IC patients who received a deceased donor transplant still had a potential LD being worked up. It is unclear why deceased donor transplantation was more common for HC patients, since the groups did not differ significantly on waiting time, dialysis, or dialysis duration – important kidney allocation variables in our region. Differences in blood type, PRA, organ turndown rate, and transitions from active to inactive listing status could also account for differential rates of deceased donor transplant, but unfortunately we did not collect these data prospectively. Another possible explanation is a difference in willingness to accept ECD/DCD kidneys, which could contribute to an imbalance in rates of deceased donor transplantation. Of the 11 HC patients who received deceased donor transplants, 5 (46%) were ECD kidneys, compared to 22% for GB patients and only 17% for IC patients.

Surprisingly, the LDKT rate in the current study is lower than what we found for black patients in our earlier HC study (16% vs. 45%),[14] despite a higher proportion of patients in the current study with at least one LD inquiry (82% vs. 77%) and at least one LD evaluation (65% vs. 48%). Several factors could account for these discrepant findings. The

studies were conducted nearly a decade apart at two different centers in two geographically distinct regions of the United States (Florida and Massachusetts) with different donor evaluation processes and selection criteria. Black patients in the prior study were a homogeneous group with African ancestry residing in rural regions. Most had multi-generational ties to the region and larger extended families in close proximity. In contrast, the current study recruited more diverse black patients from an urban region and who had more shallow roots and more dispersion of extended family members throughout the United States and other countries. Also noteworthy is that the current study was conducted in an era of increased regulatory oversight of LD and transplant center performance,[18-20] more complex histocompatibility testing, a more protracted evaluation process, more restrictive selection criteria for black donors due to less favorable long-term outcomes,[21-23] and a national decline in LDKT, particularly among blacks.[15] All of these factors may have contributed to lower LDKT rates in the current study, although we did not evaluate in either study the reasons why potential donors did not progress to donation.

The randomized controlled design, recruitment and retention of a large black sample, use of validated measures of secondary outcomes, and implementation of novel LDKT educational interventions are notable strengths of the study. However, there are some notable limitations. This is a single-center study and results may not generalize beyond the characteristics and processes of our transplant center. All three interventions were single-contact educational sessions, which may lack the intensity necessary for patients with historically low LDKT rates. Additionally, we enrolled patients at any LDKT readiness stage. The inclusion of patients in later stages of readiness may have limited estimates of the HC intervention's effectiveness. Some cell sizes in our secondary analyses were small and may not have had sufficient power to detect significant differences. Finally, some constructs that may be associated with eventual LDKT (e.g., self-efficacy in being able to find a donor, medical distrust, health literacy) were not measured.[8,24,25]

In conclusion, racial inequities persist for blacks in need of transplantation.[6,7,9,26-30] Recent innovative interventions have been developed to address these disparities, with a particular focus on overcoming LDKT barriers.[17,31-34] However, these interventions do not have the same reach into the patient's social network as does the HC intervention. Considering that more than one-third of living donors in the United States now come from beyond the patient's immediate family, educational efforts such as the HC intervention that directly involve the patient's social network will help catalyze the patient's LD discussions with others, facilitate more LD inquiries and evaluations, and thereby increase the likelihood of LDKT. Additional clinical trials of the HC intervention are underway and will provide further evaluation of its effectiveness with diverse populations.[35]

METHODS

Design

This is a single-center RCT with urn randomization [36,37] into one of three LDKT educational intervention groups in which the content and dose were standardized as much as possible. Questionnaires were completed pre-intervention (before randomization) and 1 and 6 weeks following the intervention. Data on LD inquiries, evaluations, and transplantation

were collected monthly until 2 years post-intervention. The protocol was approved by the BIDMC IRB and registered with ClinicalTrials.gov (NCT00785265).

Participants and Recruitment

Details of the patient population and study procedures are described elsewhere.[12] Inclusion criteria included: self-identification as black race, 21 years old, approved for placement on the kidney transplantation waiting list, and resides 2.5 hours driving time from the transplant center. Patients were excluded if they required multi-organ transplantation, did not speak English, had active substance abuse, or had cognitive or psychiatric disorders significant enough to interfere with study requirements. Over a 48-month period, patients meeting study eligibility and interested in participating provided informed consent, completed the pre-intervention assessment, and were then randomized to intervention group.

Interventions

We previously described the common and distinct features of the interventions.[12] All interventions were: (1) single 60-90 minute session, (2) designed for in-depth discussion of LDKT and LD, (3) led by health educators, (4) culturally sensitive, and (5) supplemented with identical video and print materials. LDKT and LD topics (n=22) were selected a priori and included information about transplant patient and LD eligibility, evaluation processes, outcomes, and racial disparities, as well as common concerns of patients and potential donors, financial issues, and kidney paired donation, among others.[12,13] The protocol required all topics to be discussed by health educators, although the time per topic varied to allow flexibility for more discussion of issues identified by patients and/or guests as most important to them. We tried to deliver the intervention within 6 weeks of randomization, although delays were unavoidable at times. Patients and guests were paid \$10 to offset any travel expenses.

House Calls (HC)—This intervention occurred in the patient’s home, with the patient and his/her invited guests (e.g., family, friends, others). Prior to the session, patients identified guests and distributed invitations (prepared by the researchers) describing the purpose and date/time of the session. Rarely, the session was held elsewhere (e.g., a family member’s residence, local church) at the patient’s request.

Group-Based (GB)—GB patients also developed a guest list and distributed invitations to them, but the session was held in the transplant center. These sessions also included other study patients and their invited guests. This intervention was selected because it mirrors the group-based LDKT education done at some centers [38-40] and was considered a more cost-efficient alternative to HC while still including the patient’s support network.

Individual Counseling (IC)—IC patients received one-on-one education in the transplant center, typically coinciding with another clinic appointment to maximize convenience for the patient. This intervention was selected because it represents an exclusive and enhanced focus on LDKT, beyond the education that occurs in the context of regular clinic visits. Additionally, IC can be implemented with minimal resources by any program.

Outcomes(Table 4)

The primary outcome was the occurrence of LDKT within 2 years of intervention, or 2 years after randomization for patients who did not receive the allocated intervention. Secondary outcomes included whether the patient had 1 LD inquiry and 1 LD evaluation by the 2 year endpoint. Also, LDKT readiness stage, LDKT knowledge, LDKT concerns, and willingness to talk to others about LD [5,12-14] were assessed pre-intervention and at 1 and 6 weeks post-intervention. Patients were paid \$20 for completion of questionnaires at each time point. We abstracted sociodemographic and clinical data from the electronic record and administered the SF-36 Health Survey [41] pre-intervention.

Satisfaction and Fidelity

Patients and guests completed an 8-item Satisfaction Questionnaire (1=very dissatisfied, 5=very satisfied) to assess perceived clarity and usefulness of the information discussed, professionalism of the health educator(s), and overall session quality. Also, following each session, health educators completed a Session Summary Form that assessed topics discussed, session duration, number of guests (HC and GB only), and a description of any issues that affected intervention delivery.

Statistical Analyses

Pre-intervention patient sociodemographic and medical characteristics were compared using one-way analysis of variance (ANOVA) and chi-square. Analysis of the primary and secondary outcomes followed the intention-to-treat principle, with comparisons done based on the patient's assigned intervention group. Chi-square was used to compare the three groups on the primary outcome (LDKT at 2 years) and to compare the observed LDKT rates to the LDKT rate for blacks added to our center's waiting list in the past decade. The secondary outcomes of LD inquiry and evaluation occurrence were examined using chi-square. Poisson regression models were used to examine group differences in the number of LD inquiries and evaluations. General linear modeling with repeated measures (time: pre-intervention, 1 and 6 weeks post-intervention) was used to examine the secondary outcomes of LDKT knowledge, concerns, and willingness to talk to others, with multiple imputation using linear interpolation. Post hoc tests were performed following significant Group x Time interaction effects. For all analyses, we assumed data were missing at random since no specific patterns to missing data were discernible. All data were entered and analyzed using the Statistical Package for the Social Sciences (SPSS, Version 16).

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ABBREVIATIONS

ANOVA	Analysis of Variance
BIDMC	Beth Israel Deaconess Medical Center
GB	Group-Based
HC	House Calls
IC	Individual Counseling
IRB	Institutional Review Board
LD	Living Donation
LDKT	Live Donor Kidney Transplantation
RCT	Randomized Clinical Trial

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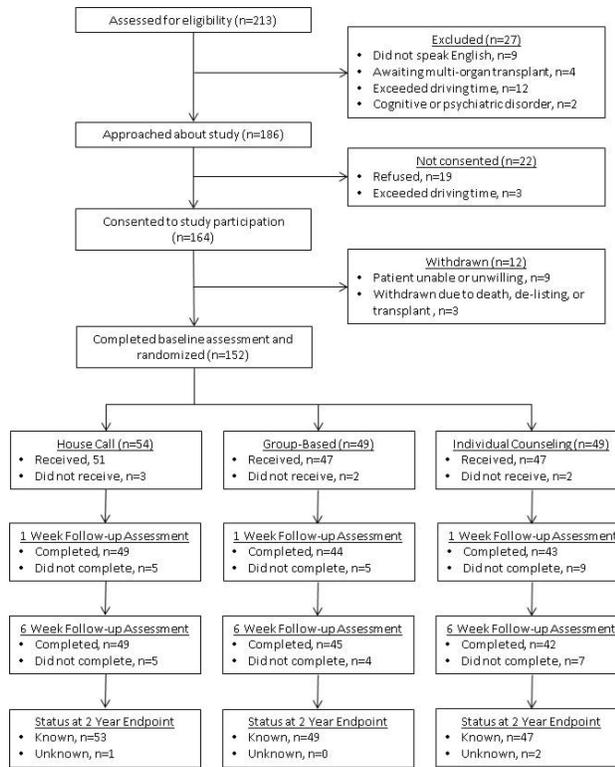


Figure 1.
Study flowchart.

Table 1

Baseline sociodemographic and clinical characteristics of randomized study participants

	House Calls (n = 54)	Group-Based (n = 49)	Individual Counseling (n = 49)	^a p
Sociodemographic characteristics				
Age, M (sd)	50.9 (12.4)	51.8 (12.3)	51.4 (12.5)	0.93
Female sex, % (n)	42.6 (23)	44.9 (22)	40.8 (20)	0.92
Education				0.70
high school, % (n)	38.9 (21)	36.7 (18)	46.9 (23)	
Some college, % (n)	24.1 (13)	32.7 (16)	24.5 (12)	
College or post-graduate degree, % (n)	37.0 (20)	30.6 (15)	28.6 (14)	
Employed, % (n)	37.0 (20)	36.7 (18)	32.7 (16)	0.88
Married or partnered, % (n)	46.3 (25)	36.7 (18)	34.7 (17)	0.43
Clinical characteristics				
Primary renal disease etiology				0.83
Diabetes, % (n)	40.7 (22)	34.7 (17)	38.8 (19)	
Hypertension, % (n)	27.8 (15)	34.7 (17)	24.5 (12)	
Other, % (n)	31.5 (17)	30.6 (15)	36.7 (18)	
Dialysis, % (n)	79.6 (43)	83.7 (41)	85.7 (42)	0.70
Dialysis duration, mos., M (sd) ^b	34.8 (46.2)	35.1 (34.7)	39.9 (35.5)	0.80
Length of time on waiting list, mos, M (sd)	15.4 (24.6)	18.0 (27.5)	17.4 (23.6)	0.87
Prior kidney transplant, % (n)	11.1 (6)	10.2 (5)	10.2 (5)	0.96
Quality of life (SF-36)				
Physical, M (sd)	38.5 (10.5)	39.1 (11.3)	36.7 (10.6)	0.49
Mental, M (sd)	49.4 (11.7)	48.6 (10.7)	46.9 (12.1)	0.53

^aF test for continuous variables; chi-square (χ^2) for categorical variables.^bCalculated only for patients on dialysis at study enrollment.

Table 2

Patient status at 2 year study endpoint.

	House Calls (n = 54)	Group-Based (n = 49)	Individual Counseling (n = 49)	p
Live donor kidney transplantation (LDKT), % (n)	14.8 (8)	8.2 (4)	6.1 (3)	0.30
Time from intervention to LDKT, mos., M (sd)	8.0 (2.8)	7.8 (4.3)	10.0 (6.2)	0.72
Pre-emptive, % (n)	9.3 (5)	2.0 (1)	2.0 (1)	0.13
Deceased donor kidney transplantation, % (n)	20.4 (11)	18.4 (9)	12.2 (6)	0.53
Time from intervention to DDKT, mos., M (sd)	11.9 (7.6)	13.6 (7.1)	13.0 (7.2)	0.88
Not transplanted, % (n)	63.0 (34)	73.5 (36)	77.6 (38)	0.24
On waiting list	85.3 (29)	75.0 (27)	86.8 (33)	
Removed from waiting list ^a	5.9 (2)	13.9 (5)	5.3 (2)	
Died	8.8 (3)	11.1 (4)	7.9 (3)	
Unknown status	1.9 (1)	0 (0)	4.1 (2)	0.35

^aReasons for removal: too sick for transplant (n=6), patient preference (n=2), and other factors (n=1).

Table 3

LDKT readiness stage, knowledge, concerns, and willingness by intervention group over time.

	House Calls			Group-Based			Individual Counseling			p
	Baseline	1 wk	6 wk	Baseline	1 wk	6 wk	Baseline	1 wk	6 wk	
LDKT readiness stage, %										0.001 ^a
Pre-contemplation	24%	4%	2%	24%	9%	11%	37%	12%	12%	
Contemplation	33%	10%	2%	31%	23%	23%	31%	33%	33%	
Preparation	32%	46%	24%	33%	46%	32%	22%	44%	41%	
Action	9%	32%	54%	10%	20%	32%	8%	9%	12%	
Maintenance	2%	8%	18%	2%	2%	2%	2%	2%	2%	
LDKT knowledge, M	9.9	12.9	13.2	9.7	12.0	12.0	9.4	11.1	11.3	0.007 ^b
LDKT concerns, M	38.9	32.4	31.5	38.9	34.3	34.5	39.9	37.7	38.6	0.005 ^b
Willingness to talk to others, M	3.7	5.2	6.1	3.9	4.7	5.1	3.4	4.0	3.9	<0.001 ^b

^a A higher proportion of patients in the House Calls group were in Action and Maintenance stages compared to Group-Based and Individual Counseling patients at 6 weeks post-intervention. There was no significant group difference in readiness stage at the baseline or 1 week post-intervention assessment.

^b Group (3) × Time (3) interaction effect (Wilks' Lambda)

Table 4

Description of primary and secondary outcomes

Outcomes	Description
Primary Outcome	
Live donor kidney transplant (LDKT)	LDKT 2 years following study intervention (yes, no)
Secondary Outcomes	
Living donor inquiry	A request by a family member, friend, or acquaintance for more information about living donation (yes, no) and absolute number of inquiries
Living donor evaluation	Completion of blood compatibility testing and/or health screening by nurse coordinator (yes, no) and absolute number of evaluations initiated
LDKT readiness stage	1 item assessing readiness to pursue LDKT: "I am not thinking about or considering LDKT." (Pre-contemplation) "I am now beginning to think about or consider LDKT." (Contemplation) "I have thought about LDKT and I am seriously considering this possibility." (Preparation) "I have thought about LDKT, and I have talked to someone who is willing to be evaluated as a possible living donor." (Action) "I have thought about LDKT and I have someone who has initiated evaluation to be a living donor." (Maintenance)
LDKT knowledge	16 statements assessing knowledge of LDKT and living donation (true-false; score range 0 to 16; higher score = more knowledge)
LDKT concerns	21 items reflecting possible concerns about pursuing LDKT(1=not at all concerned, 5=extremely concerned; score range 21 to 105; higher score = more concerns)
Willingness to talk to others	1 item assessing willingness to talk to family members or friends about possible living kidney donation (1=not at all willing, 7=extremely willing)