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Direct Delivery of Kidney Transplant Education to Black and Low-Income Patients Receiving Dialysis: A Randomized Controlled Trial

Amy D. Waterman, John Devin Peipert, Anna-Michelle McSorley, Christina J. Goalby, Jennifer L. Beaumont, and Leanne Peace

Rationale & Objective: Compared with others, black and low-income patients receiving dialysis are less likely to receive kidney transplantation (KT) education within dialysis centers. We examined the efficacy of 2 supplementary KT education approaches delivered directly to patients.

Study Design: Prospective, 3-arm parallel-group, randomized, controlled trial.

Settings & Participants: Adult, black, and white low-income patients receiving dialysis in Missouri.

Intervention: Patients were randomly assigned to 1 of 3 educational conditions: (1) standard of care, usual KT education provided in dialysis centers (control); (2) Explore Transplant @ Home patient-guided, 4 modules of KT education sent directly to patients using print, video, and text messages; and (3) Explore Transplant @ Home educator-guided, the patient-guided intervention plus 4 telephonic discussions with an educator.

Outcomes: Primary: patient knowledge of living (LDKT) and deceased donor KT (DDKT). Secondary: informed decision making, change in attitudes in favor of LDKT and DDKT, and change in the number of new steps taken toward KT.

Results: In intent-to-treat analyses, patients randomly assigned to educator- and patient-guided interventions had greater knowledge gains (1.4 point increase) than control patients (0.8 point increase; $P = 0.02$ and $P = 0.01$, respectively). Compared with control patients, more patients randomly assigned to educator- and patient-guided interventions were able to make informed decisions about starting KT evaluation (82% vs 91% and 95%; $P = 0.003$), pursuing DDKT (70% vs 84% and 84%; $P = 0.003$), and pursuing LDKT (73% vs 91% and 92%; $P < 0.001$).

Limitations: Potential contamination because of patient-level randomization; no assessment of clinical end points.

Conclusions: Education presented directly to dialysis patients, with or without coaching by telephone, increased dialysis patients' KT knowledge and informed decision making without increasing educational burden on providers.

Funding Source: This project was funded by the National Institutes of Health and Health Resources and Services Administration.

Trial Registration: Registered at [ClinicalTrials.gov](https://clinicaltrials.gov) with study number NCT02268682.

Complete author and article information provided after references.

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In the United States, more than 678,000 patients have kidney failure, with nearly 100,000 diagnosed annually.¹ Kidney transplantation (KT) can help patients live longer with improved quality of life compared to ongoing dialysis.² Per the Centers for Medicare & Medicaid Services, every maintenance dialysis patient must be informed of their KT options, including whether to continue dialysis or pursue either a deceased (DDKT) or living donor KT (LDKT).³ Despite available KT education, >70% of patients with kidney failure remain on dialysis therapy.¹

In addition, lack of access to KT affects some patients disproportionately. In the United States, black patients are 3.1 times more likely than white patients to develop kidney failure but are less likely to receive transplants,¹ especially living donor kidney transplants,⁴ due to poorer KT knowledge,⁵ greater fears of KT in general and LDKT specifically,⁶⁻⁸ higher medical mistrust,⁷⁻¹⁰ and greater socioeconomic burdens.⁹ Independent of race, patients with low socioeconomic status (SES) are up to 75% less likely to receive living donor kidney transplants.¹¹⁻¹⁴ The challenges of these additional

barriers to KT for low-SES black patients add complexity to learning about DDKT and LDKT.

The American Society of Transplantation recommends providing culturally tailored community-based LDKT education to patients earlier in the transplantation referral process, in modules, with transplantation liaisons in dialysis clinics.¹⁵ Supplementary education provided directly to dialysis patients over a longer time frame may enhance current KT education in dialysis centers. Text-messaging interventions^{16,17} could be used because these have been shown to promote behavior change.¹⁷ For patients with complex medical situations and low SES, the use of telephonic case managers¹⁸⁻²⁰ has helped provide individualized support and education remotely. These educational strategies and delivery approaches have not yet been studied in combination for patients learning about DDKT and LDKT. Thus, we conducted a randomized controlled trial (RCT) testing whether an 8-month Explore Transplant @ Home education program, with or without telephonic support from an educator, could help improve transplantation

knowledge, informed decision making, pro-transplantation attitudes, and steps toward KT compared to traditional dialysis center KT education for low-income black and white patients.

Methods

RCT Design

This study was a prospective parallel-arm RCT among 561 black and white dialysis patients in Missouri. Patients were recruited from the Missouri Kidney Program client roster or from public advertisements in dialysis centers. The Missouri Kidney Program is a state-funded organization providing financial assistance to low-income Missouri residents with kidney failure. Patients were randomly assigned to receive 1 of 3 educational conditions over 8 months: standard transplantation education provided in dialysis centers only (standard of care), the patient-guided Explore Transplant @ Home program without access to a telephonic educator, or the educator-guided Explore Transplant @ Home program facilitated by a telephone educator. The published protocol²¹ was registered at [ClinicalTrials.gov](https://www.clinicaltrials.gov) (#NCT02268682) and approved by the University of California, Los Angeles Institutional Review Board (#14-000802) and the University of Missouri, Columbia Institutional Review Board (#00048966).

Setting and Participants

Participants came from 122 unique dialysis centers representing multiple dialysis organizations. Patient inclusion criteria were: (1) aged between 18 and 74 years, (2) self-identify as black or white, (3) currently receiving dialysis, (4) household income \leq 250% of the federal poverty level, and (5) speak and read English. Patients were excluded if they: (1) had a visual and/or hearing impairment that would preclude watching and reading education, (2) had a previous KT, and/or (3) had previously been told that they were not a candidate for transplantation. Missouri Kidney Program patients received flyers within prescription medication packets mailed to their homes, and flyers were disseminated in nearly 100 Missouri dialysis facilities. Interested patients contacted the study team directly to assess eligibility and provide verbal informed consent to participate.

Explore Transplant @ Home Patient-Guided Education Condition (intervention 1)

Patients randomly assigned to the patient-guided intervention received standard of care plus an 8-month educational program, including 4 video and print modules mailed every 2 months containing brochures, fact sheets, and an Explore Transplant DVD video, averaging 20 minutes in length, to watch at home with family or friends. If patients did not have a DVD player, one was provided for them at no charge. Additionally, 12 postcards

were mailed, 1 every 2 weeks, with educational highlights from each module. Finally, patients could opt to receive text messages repeating content and asking multiple choice and true/false questions to facilitate learning each week.

Explore Transplant @ Home Educator-Guided Education Condition (intervention 2)

Patients randomly assigned to the educator-guided intervention received standard of care and the complete patient-guided intervention over 8 months. In addition, they received calls with an educator who reviewed key educational concepts from each module, probed to determine whether the patient had any questions, and strategized with the patient about overcoming barriers they might face in making decisions about transplantation. Calls lasted approximately 20 minutes.

Standard-of-Care Dialysis Center Education Condition (control)

Patients randomly assigned to the standard of care received only transplantation education provided as part of usual care within their dialysis centers. Based on the results of our survey of Missouri dialysis providers, this education varied substantially. Though 57% said there was a formal education program in their center, the most common education practices included oral recommendations that patients get evaluated for transplantation (93%) or learn more about transplantation (89%) and dissemination of print KT materials (74%). Only 15% showed educational videos, 20% offered opportunities to talk about transplantation with a kidney recipient, and 24% provided education to share with potential living donors (Table 1).

Outcome Measures

All patients were administered prerandomization and post-intervention surveys. The primary outcome was patients' knowledge of LDKT and DDKT. The transplantation knowledge scale had 15 questions, 10 true/false and 5 multiple choice, scored so that correct responses contributed 1 point and incorrect or "don't know" responses contributed 0 point. The total correct responses were summed to create a scale of 0 to 15, with higher scores indicating higher transplantation knowledge.

Secondary outcomes included informed decision making, LDKT and DDKT attitudes, and new steps toward transplantation. The postintervention survey included 4 questions asking whether the patient had all the facts they needed to make an informed decision about whether to remain on dialysis, start KT evaluation, and try to get a deceased donor and/or living donor kidney transplant. To each, patients rated their agreement on a 4-point scale from "completely agree" to "completely disagree," and the proportion of patients responding that they agreed was assessed.

LDKT and DDKT attitudes were measured pre- and postintervention with Pros, Cons, and Self-efficacy scales

Table 1. Standard of Care of Educational Practices Used by Dialysis Providers

Description of Educational Practice	Affirmative Response or Confirmed Use of Practice	
General Approaches to Transplantation Education		
Transplantation information provided at least once to all transplantation candidates, regardless of whether they have expressed interest in transplantation	97%	
There is a formal transplantation education program at this center	57%	
There is a designated transplantation educator or team of educators at this facility	41%	
Transplantation information is provided every year to all transplantation candidates, regardless of whether they have expressed interest in transplantation	4%	
Transplantation Education Practices		
Recommend to get evaluated for transplantation	93%	
Recommend to learn more about transplantation	89%	
Provide a list of transplantation centers' telephone numbers	89%	
Provide handouts/brochures about transplantation	74%	
Display transplantation posters in the dialysis facility waiting room	61%	
Refer to an education program at a transplantation center/kidney organization	61%	
Have detailed discussions about the risks/benefits of deceased donor transplantation	35%	
Have detailed discussions about the risks/benefits of living donor transplantation	33%	
Provide list of transplantation websites	28%	
Provide patients with transplantation education to share with potential living donors	24%	
Offer an opportunity to talk to a previous transplant recipient	20%	
Show transplantation video(s) or DVD(s)	15%	
There is not good communication between nearby transplantation centers and this dialysis facility	28%	
There is not enough time to educate patients about transplantation	28%	
Do not have a DVD player to watch educational videos	23%	
The transplantation centers are too far away from this facility	22%	
My dialysis facility administration does not value transplantation education as a priority	9%	

Note: n = 46. Results of survey of dialysis staff representatives of 46 dialysis centers in which patients in this study received care. We asked what general approaches to transplantation education were used in the dialysis center and whether they used any of 12 transplantation education practices. We also asked the dialysis staff about the barriers they faced to providing transplantation education in their center.

(6 scales total).^{22,23} The LDKT and DDKT Pros and Cons scales each had 6 items prompted with "How important is this statement to your decision about transplant?" rated on a 5-point scale from 1, "not important," to 5, "extremely important" and summed to create scales ranging from 6 to 30, with higher scores indicating higher Pros or Cons. The LDKT and DDKT Self-efficacy scales had 6 and 8 items, respectively, asking about potential barriers that may arise to pursuing transplantation and prompted with "If you wanted a transplant and you encountered any of the following situations along the way, how confident are you that you could continue pursuing transplant?" that were rated on a 5-point scale from 1, "not at all confident," to 5, "completely confident." Responses were summed creating scores from 6 to 30 (LDKT Self-efficacy) and 8 to 40 (DDKT Self-efficacy); higher scores indicated higher self-efficacy.

Finally, patients were asked whether they had "already done," "plan to do," or "don't plan to do" 11 small steps related to taking transplantation actions (eg, "Do you plan to call the transplant center to begin evaluation?"). Patients who said they had not "already done" the action on the preintervention survey but reported having done so on the postintervention survey were counted as having newly taken the step.

Other Measures

Demographic and clinical characteristics measured pre-intervention included race, sex, age, education, health insurance type, sources of income, financial stability, dialysis type, date dialysis started, preferred communication mode, and health-related quality of life.²⁴ We asked each patient whether they had previously read transplantation brochures (yes/no) or watched transplantation videos (yes/no). Health literacy was examined by asking how often patients required help reading hospital materials. Finally, we assessed the quality of social support that a patient had (discrepancy between self-reported amount of social support needed and received) and medical mistrust (mean of 7 items of the Medical Mistrust Index).²⁵

Statistical Analyses

Details of the power analysis have previously been provided.²¹ We used a Bonferroni correction to adjust the α for multiple comparisons ($0.05/3 = 0.017$) among the 3 conditions. We calculated that 150 patients per condition would achieve 80% power to detect a 1-point difference in change in transplantation knowledge between educational conditions. For continuous outcomes, to aid in the interpretation of differences, standardized effect sizes were

calculated as the mean difference in changes from pre- to postsurvey divided by the change score standard deviation (Cohen's *d*). For categorical or count outcomes, odds or incident rate ratios (IRRs) were used as effect size estimates. *P* values presented in the results should be compared to the Bonferroni-corrected α value (0.017).

Because patients were clustered within dialysis centers, multilevel random-effects models were used, modeling the dialysis center with a random intercept. The modified intent-to-treat analysis set included all patients who completed the study regardless of participation in the education activities. A supplemental analysis included only patients participating in the education process according to the condition-specific protocol plan. Specifically, this included patients in the patient-guided condition who reported reading the print material and watching the videos and patients in the educator-guided condition who both read and watched the Explore Transplant @ Home program and attended all 4 telephone sessions.

Baseline characteristics were compared across educational conditions with Rao-Scott χ^2 tests and multilevel random-effects linear regression models. For analysis of the primary outcome, transplantation knowledge, a

multilevel random-effects regression model with a random intercept for dialysis center was used to estimate the difference in change in knowledge between educational conditions by a difference-in-differences approach. In the presence of missing data, this maximum likelihood-based modeling strategy produces unbiased estimates under an assumption that the missing data are missing at random, conditional on the observed data. Causal interpretation of the results rests on a stricter assumption of missing completely at random. A similar modeling strategy was applied for the secondary outcomes of DDKT and LKDT attitudes (Pros, Cons, and Self-efficacy). Differences between the educational conditions in the count of new steps was analyzed with a multilevel random effects Poisson model. Finally, because informed decision making was assessed only postintervention, proportional differences between educational conditions were examined with Rao-Scott χ^2 tests to account for clustering within dialysis centers.

Exploratory analyses were conducted to evaluate possible heterogeneity of effect of the interventions, compared to control, by educational background, potential transplantation derailers, or baseline outcome. Because this

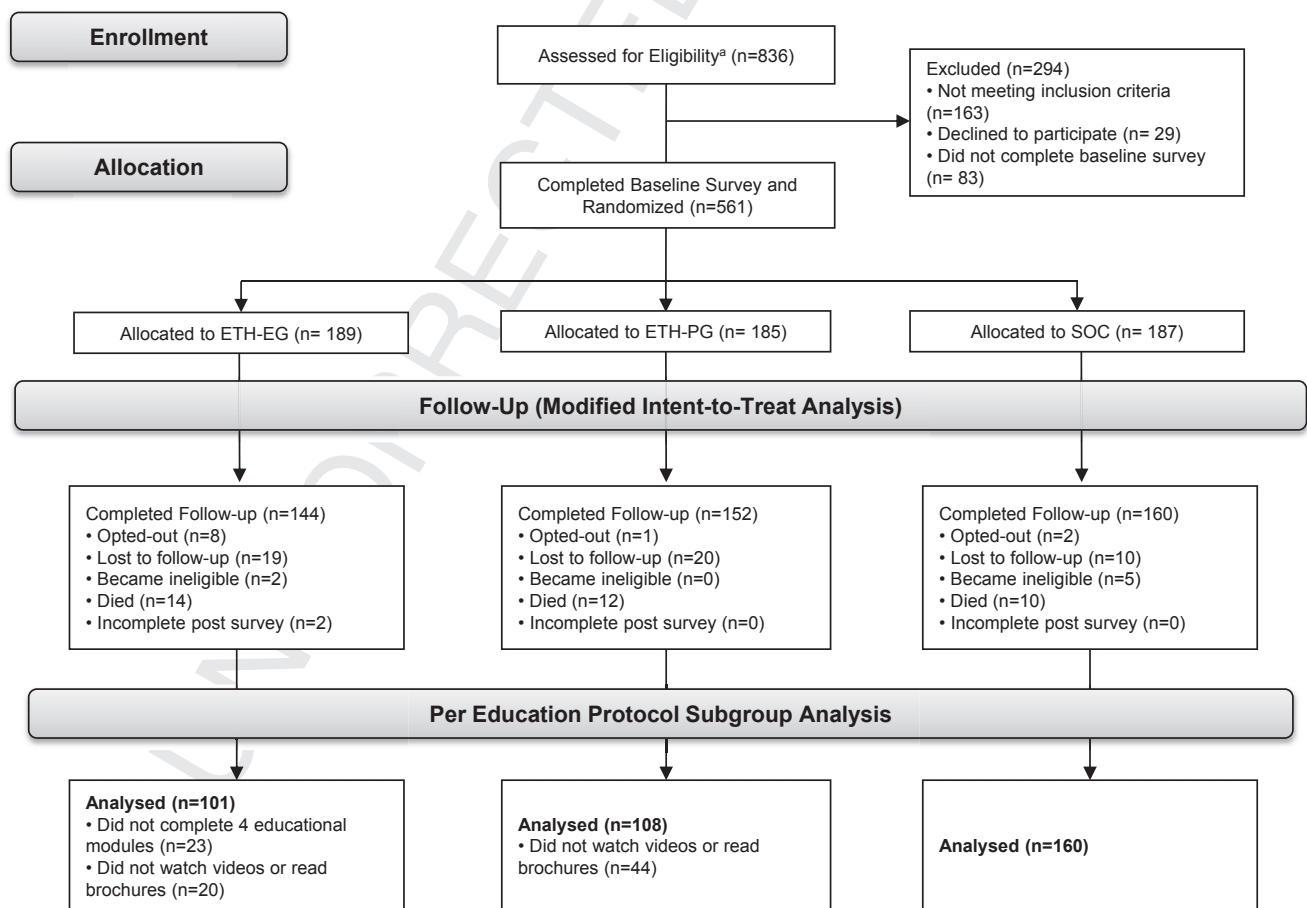


Figure 1. Study flow chart for patient selection. Abbreviations: ETH-EG, Explore Transplant @ Home educator guided; ETH-PG, Explore Transplant @ Home patient guided; SOC, standard of care.

Table 2. Dialysis Patient Participant Characteristics in the Modified Intent-to-Treat Sample

	Intervention			P
	Educator Guided (n = 189)	Patient Guided (n = 185)	Standard of Care (n = 187)	
Black race	70%	72%	71%	0.9
Female sex	51%	48%	48%	0.7
Age, y	54 ± 12	54 ± 10	53 ± 10	0.6
PKD as cause of kidney failure	8%	7%	6%	0.8
Education level				0.2
≤High school diploma	57%	48%	54%	
Some college	31%	37%	29%	
≥College graduate	12%	15%	17%	
Health insurance				0.3
Medicare (national medical card)	88%	90%	84%	
Medicaid (state medical card)	8%	6%	10%	
Private insurance (HMO or PPO)	1%	2%	4%	
Other insurance	3%	2%	2%	
Source of income ^a				
Full-time employment	2%	1%	1%	0.9
Retirement savings/pension	4%	4%	6%	0.8
Social Security (retirement)	34%	27%	25%	0.09
Disability due to kidney disease	59%	59%	68%	0.1
Disability due to other causes	20%	27%	24%	0.3
If family lost current income, how long could you live in your current situation?				0.3
<1 mo	45%	46%	37%	
1-6 mo	33%	26%	39%	
>7 mo	22%	27%	24%	
Hemodialysis as dialysis modality	94%	92%	93%	0.8
Dialysis vintage, y	4 [1-8]	5 [2-7]	3 [1-8]	0.8
Preferred mode of communication				0.2
Telephone	98%	93%	94%	
Mail	0%	2%	1%	
E-mail	1%	2%	2%	
Text message	1%	3%	3%	
Previously read transplantation brochures	72%	75%	76%	0.6
Watched transplantation videos	23%	31%	30%	0.1
How often requires help reading hospital materials				0.2
Never	54%	58%	52%	
Any time	46%	42%	48%	
Has needed social support	73%	78%	78%	0.4
Medical mistrust ^b	2.8 ± 0.6	2.8 ± 0.7	2.9 ± 0.6	0.2
General health score ^c	3.3 ± 1.0	3.4 ± 0.9	3.5 ± 1.0	0.1

Note: n = 561. Values for continuous variables given as mean ± standard deviation or median [interquartile range].

Abbreviations: HMO, health maintenance organization; HROQL, health-related quality of life; PKD, polycystic kidney disease; PPO, preferred provider organization.

^aPatients could check all appropriate options; therefore, percentages down columns do not sum to 100%.

^bScore ranges from 1 to 4, with higher scores reflecting higher medical mistrust.

^cBy Centers for Disease Control and Prevention HRQoL-4; score ranges from 0 to 5, with higher scores reflecting higher HRQoL.

study was not powered to detect interaction effects, this work was exploratory and P values were not calculated.

Results

Participants

In response to advertisements, 836 patients called for eligibility assessment. Of the 673 eligible patients, 83% (n = 561) completed a baseline survey and were randomly

assigned, with 189 allocated to the educator-guided Explore Transplant @ Home condition; 185, to the patient-guided Explore Transplant @ Home condition; and 187, to the standard-of-care control group (Fig 1). After omitting patients who withdrew, died, or were lost to follow-up, 456 patients remained, with 144 (76%) in the educator-guided condition, 152 (82%) in the patient-guided condition, and 160 (86%) in the control group. This represents the modified intent-to-treat sample.

For the supplemental analyses in the per-education protocol subgroup, 43 educator-guided intervention patients were omitted for not completing all 4 telephone education modules ($n = 23$) and not reading the brochures or watching the videos ($n = 20$); 44 patient-guided intervention patients were omitted for not reading the brochures or watching the videos. This analysis sample consisted of 369 patients (101 educator-guided intervention, 108 patient-guided intervention, and 160 control group).

There were no baseline differences between the randomly assigned education conditions (Table 2). The largest proportion of patients were black (70%-72%), had a high school diploma or less (48%-57%), used Medicare for health insurance (84%-90%), relied on income from disability benefits due to kidney disease (59%-68%), could live in their current situation for less than 1 month if income were lost (37%-46%), and were receiving hemodialysis (92%-94%). Most participants had read transplantation brochures before joining the study (72%-76%), but few had watched videos about transplantation (23%-31%). Characteristics of the per-education protocol subset of patients are in Table S1.

Primary Outcome: Transplantation Knowledge

At baseline, mean transplantation knowledge score was 7.2 (SD, 2.3; range, 0-14), indicating that patients responded correctly to <50% of the 15 questions. In comparison to the control group, significant increases in transplantation knowledge were observed for the educator- and patient-guided conditions (Fig 2). The difference-in-differences analysis yielded the following estimated differences in knowledge increases between conditions: 0.6 ($d = 0.26$) for educator-guided intervention versus control ($P = 0.02$) and 0.7 ($d = 0.30$) for patient-guided intervention versus control ($P = 0.01$; Table 3). There was no heterogeneity of intervention effects on knowledge for any of the factors examined. The supplemental analysis produced similar results (Table S2).

Secondary Outcomes: LDKT and DDKT Attitudes (pros, cons, and self-efficacy)

Marginally significant increases in LDKT and DDKT Pros were observed for educator-guided intervention compared to the control group. The difference-in-differences analysis yielded the following estimated differences in score changes: LDKT Pros, 1.3 ($d = 0.27$) for educator-guided intervention versus control group ($P = 0.03$); DDKT Pros, 1.03 ($d = 0.22$) for educator-guided intervention versus control ($P = 0.04$); DDKT Cons, -1.5 ($d = 0.25$) for educator-guided intervention versus control ($P = 0.03$); and DDKT Self-efficacy, 1.9 ($d = 0.28$) for educator-guided intervention versus control ($P = 0.03$; Table 3). No significant differences between the patient-guided intervention and control groups were observed. The supplemental analysis produced similar results (Table S3).

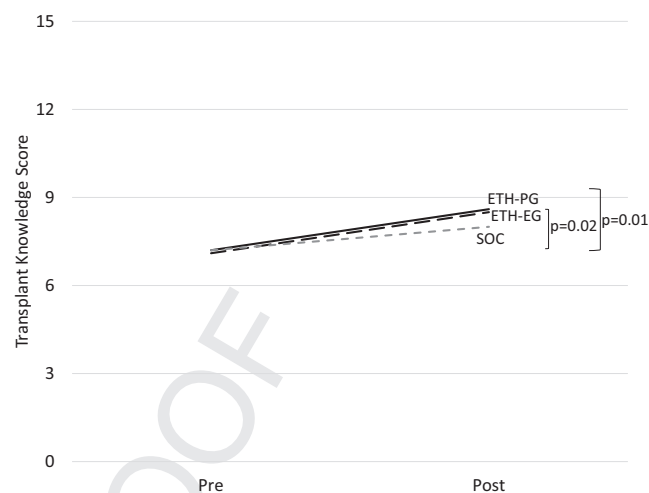


Figure 2. Pre- to postchange in transplantation knowledge educational condition – modified intent-to-treat sample. Abbreviations: ETH-EG, Explore Transplant @ Home educator-guided condition; ETH-PG, Explore Transplant @ Home patient-guided condition; SOC, standard-of-care education condition. ETH-EG vs SOC, $P = 0.02$; ETH-PG vs SOC, $P = 0.01$.

There were some notable differences in the effects of each educational condition within subgroups. The educator-guided intervention more effectively increased LDKT Self-efficacy for patients with insufficient social support (6.6 [95% CI, 2.6 to 10.6] points) than for those with sufficient social support (0.2 [95% CI, -2.0 to 2.4] points), as well as for those with higher baseline LDKT Pros (5.3 [95% CI, 2.3 to 8.2] points) than lower LDKT Pros (-1.3 [95% CI, -3.9 to 1.2] points). The patient-guided intervention more effectively increased LDKT Self-efficacy for patients with higher baseline transplantation knowledge (4.3 [95% CI, 1.5 to 7.1] points) than for those with less knowledge (-1.7 [95% CI, -4.2 to 0.8] points).

Secondary Outcome: New Steps Toward Transplantation

At baseline, patients reported having completed a median of 2 of 11 steps toward transplantation (interquartile range, 0-4). The most common steps that patients completed at baseline included calling the transplantation center to begin KT evaluation (40%) and talking to transplant recipients about their experiences (34%). For all patients enrolled, the most common new steps taken between pre- and postsurvey were: (1) sharing interest in LDKT with friends and family (25%), (2) talking to transplant recipients about their experiences (23%), (3) calling the transplantation center to begin KT evaluation (17%), (4) making a list of potential living donors (17%), (5) talking to living donors about their experiences (16%), and (6) telling a transplantation coordinator of their interest in LDKT (15%).

Table 3. Difference-in-Differences Analysis of Pre- to Postchange Between Educational Conditions in Transplantation Knowledge, LDKT Attitudes, and DDKT Attitudes in the Modified Intent-to-Treat Analysis

	Intervention						Standard of Care			Difference-in-Differences (vs standard of care) ^a	
	Educator Guided (n = 144)			Patient Guided (n = 152)			Standard of Care (n = 160)				
	Pre	Post	Diff	Pre	Post	Diff	Pre	Post	Diff	Educator Guided	Patient Guided
Transplantation knowledge	7.1	8.5	+1.4	7.2	8.6	+1.4	7.2	8.0	+0.8	0.6 (0.3); P = 0.02	0.7 (0.3); P = 0.01
LDKT Pros	24.3	25.1	+0.8	25.4	25.4	0	25.5	25.0	-0.5	1.3 (0.6); P = 0.03	0.4 (0.6); P = 0.5
LDKT Cons	20.5	19.8	-0.7	19.4	19.6	+0.2	19.7	19.8	+0.1	-0.7 (0.9); P = 0.4	0.1 (0.9); P = 0.9
LDKT Self-efficacy	21.3	21.2	-0.1	23.0	22.4	-0.6	22.5	20.9	-1.6	1.5 (0.9); P = 0.1	1.0 (0.9); P = 0.3
DDKT Pros	25.9	26.8	0.8	26.5	26.6	0.1	27.0	26.8	-0.2	1.0 (0.5); P = 0.04	0.3 (0.5); P = 0.6
DDKT Cons	21.5	19.4	-2.2	20.6	19.8	-0.8	21.4	20.8	-0.6	-1.5 (0.7); P = 0.03	-0.2 (0.7); P = 0.8
DDKT Self-efficacy	30.8	31.5	0.7	33.2	32.2	-1.0	33.4	32.2	-1.2	1.9 (0.9); P = 0.03	0.2 (0.9); P = 0.8

Note: n = 456.

Abbreviations: DDKT, deceased donor kidney transplantation; LDKT, living donor kidney transplantation.

^aDifference-in-differences b estimate (standard error).

In a random-effects Poisson model, the count of new steps taken by those in the patient-guided condition was marginally higher than that of those in the control group: IRR, 1.21 (95% CI, 1.01-1.47); P = 0.04. However, there was no difference between the educator-guided and control group conditions: IRR, 1.04 (95% CI, 0.85-1.27); P = 0.4 (Table 4). Only 1 subgroup difference was notable when examining heterogeneity of intervention effects. The educator-guided intervention more effectively increased the number of steps taken toward KT compared to the control group among patients with more than a high school education (IRR, 2.20; 95% CI, 1.55-3.13), while patients with a high school education or less had a reduced number of steps taken compared to the control group (IRR, 0.52; 95% CI, 0.37-0.74). The effect of patient-guided intervention was somewhat more pronounced in the supplemental analysis (Table S3).

Secondary Outcome: Informed Decision Making

Compared with control patients, significantly higher proportions of patients randomly assigned to the educator-guided and patient-guided conditions were able to make informed decisions about starting KT evaluation (82% [120/146] vs 91% [115/127] vs 95% [130/137]; P = 0.003), getting a deceased donor kidney transplant (70% [103/147] vs 84% [107/128] vs 84% [115/137]; P = 0.003), and getting a living donor kidney transplant (73% [106/145] vs 91% [116/127] vs 92% [125/136]; P < 0.001; Fig 3). Heterogeneity of intervention association with informed decision making was not examined because the small number of patients reporting an inability to make informed decisions (<20 in several instances) limits the stability of the required logistic regression models.

Discussion

Research in more than 6,000 US dialysis centers has shown that patients undergoing dialysis receive inconsistent KT

education, with black and low-income patients less likely to be educated about, referred for, and receiving kidney transplants or living donor kidney transplants.²⁶ Applying best practices,³ this study examined the value of delivering systematic education over time and in varied delivery formats to support patients with different levels of health literacy and learning styles. The RCT found that the Explore Transplant @ Home 8-month modular print, video, and texting program improved black and low-income patients' knowledge and informed decision making compared to standard education provided within dialysis centers. While the trial also assessed the value of a health educator to further enhance learning, increases in transplantation knowledge over time were not improved if Explore Transplant @ Home patients had additional support from an educator compared to just receiving modular education directly.

In comparison to the control group, both Explore Transplant @ Home programs were shown to significantly increase, from pre- to postintervention, transplantation

Table 4. Number of New Steps Taken From Pre- to Postsurvey in the Modified Intent-to-Treat Analysis

	Intervention		
	Patient Guided	Educator Guided	Standard of Care
No. of participants	144	152	160
No. of steps: pre			
Mean	2.9	2.6	2.7
Median	2.0	1.0	2.0
No. of steps: new from pre-post			
Mean	1.9	1.6	1.6
Median	1.0	1.0	1.0
IRR ^a (95% CI)	1.21 (1.01-1.47)	1.04 (0.85-1.27)	Reference
P	0.04	0.4	—

Abbreviations: CI, confidence interval; IRR, incident rate ratio.

^aIRR from Poisson model.

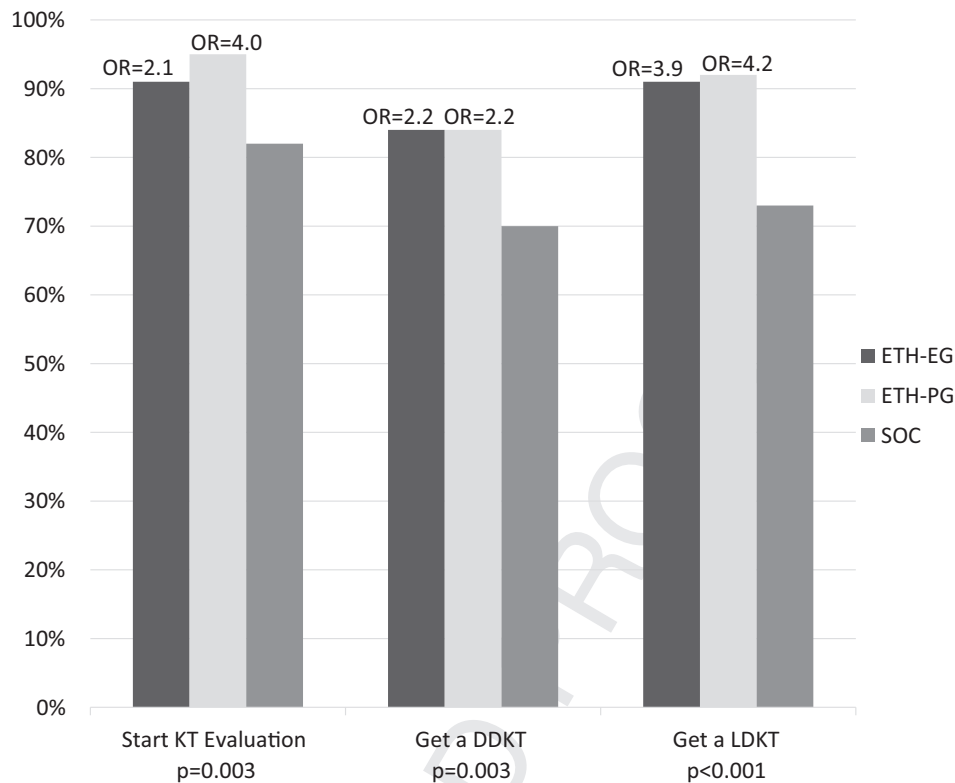


Figure 3. Differences in reported ability to make an informed decision about transplantation options at postsurvey between Explore Transplant @ Home conditions and standard of care; modified intent-to-treat analysis. Abbreviations: DDKT, deceased donor kidney transplantation; ETH-EG, Explore Transplant @ Home educator guided; ETH-PG, Explore Transplant @ Home patient guided; KT, kidney transplantation; LDKT, living donor kidney transplantation; OR, odds ratio; SOC, standard of care. ORs estimate the difference in odds of reporting being able to make an informed decision about kidney transplantation evaluation, DDKT, and LDKT for each Explore Transplant @ Home condition versus standard of care. Rao-Scott χ^2 P values are given for each overall comparison.

knowledge and informed decisions about whether to start KT evaluation and whether to pursue DDKT or LDKT. The differences in increases in knowledge observed in this trial for both Explore Transplant @ Home conditions compared to the control group were over a longer period and of similar magnitude to differences in changes over time between educational interventions presented in shorter time frames in other transplantation education trials.^{27,28} Patients who received the patient-guided rather than educator-guided intervention had the highest proportion of patients reporting that they could make informed transplantation decisions. Patients most likely to benefit from receiving supplemental Explore Transplant @ Home education included patients who already saw the benefits of LDKT at the start of the trial and those who had insufficient social support.

Finally, patient-guided intervention patients were marginally more likely to take small steps such as talking about interest in LDKT with their families than control group patients. The same was not true for educator-guided intervention patients, except in the subgroup of patients with more than a high school education. These results resemble those from the Talking About Living Kidney Donation (TALK) program trial, which compared the

efficacy of a print and video program on its own and accompanied by in-person social worker discussions about LDKT on steps of patients with chronic kidney disease toward beginning KT evaluation.²⁹ Though the TALK trial found that the discussion-oriented social worker intervention had a higher predicted probability of taking additional steps in comparison to the education-only group, this trial also found that a significantly higher proportion of patients in the education-only group took key steps such as completing the transplantation evaluation. Considering the results of the TALK trial and the present study, it remains unclear whether discussions, either in-person or by telephone, about DDKT or LDKT improve the chances of patients with kidney disease pursuing transplantation.

Because the intervention spanned 8 months, there was variability in the delivery of the intervention components and survey completion rates, which could lead to bias in the study findings. For example, 16% of educator-guided intervention patients did not complete 4 telephone sessions with an educator. Thus, in addition to the modified intent-to-treat results, we reported a supplemental analysis using only patients fully adherent to the intervention protocol. Similarly, a higher proportion of control patients

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completed the follow-up surveys versus intervention patients. Control patients were only required to complete the 2 surveys to receive the financial incentives and may have been less burdened from participating than intervention patients, who received calls, texts, postcards, and mailings and completed the surveys. Future studies should further explore the value of coaching, reduce the number of educational touchpoints, or use a shorter time frame to ensure better adherence to the intervention.

Other limitations include lack of dialysis center-level randomization. Although center-level randomization would have prevented contamination due to communication among patients across educational arms, this risk was lower because the Explore Transplant @ Home program was mailed to patients' homes, with no interventions occurring at dialysis centers. Additionally, our measures of informed decision making were single-item subjective reports and were not verified with other sources of information collected from the patients, which may lead to some bias. Further, the presence of missing follow-up data requires the fairly strong, and untestable, assumption of missing completely at random for causal interpretation. Finally, due to funder requirements, no hard clinical end points such as evaluation completion or receipt of a deceased or living donor kidney transplant could be examined. Future studies of this program must investigate the impact on these outcomes.

In conclusion, this study establishes the efficacy of the Explore Transplant @ Home program in 2 forms to increase learning and informed decision making for black and low-SES patients. A broader implication is that delivering educational content to patients directly, with the option of short telephone conversations with educators, may help increase knowledge and informed transplantation decision making for large numbers of patients receiving dialysis without placing additional burdens on dialysis providers.

Supplementary Material

Supplementary File (PDF)

Table S1: Dialysis patient participant characteristics in the per-education protocol subgroup.

Table S2: Difference-in-differences analysis of pre- to postchange between educational conditions in transplantation knowledge, LDKT attitudes, and DDKT attitudes in the per-education protocol subgroup.

Table S3: Number of new steps taken from pre- to postsurvey in the per-education protocol subgroup.

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References

1. Saran R, Robinson B, Abbott KC, et al. US Renal Data System 2017 Annual Data Report: epidemiology of kidney disease in the United States. *Am J Kidney Dis*. 2018;71(3)(suppl 1):S1-S676.
2. Neipp M, Karavul B, Jackobs S, et al. Quality of life in adult transplant recipients more than 15 years after kidney transplantation. *Transplantation*. 2006;81(12):1640-1644.
3. Centers for Medicare & Medicaid Services, HHS. Medicare and Medicaid programs; conditions for coverage for end-stage renal disease facilities. Final rule. *Fed Regist*. 2008; 15;73(73): 20369-20484.
4. Hall EC, James NT, Garonzik Wang JM, et al. Center-level factors and racial disparities in living donor kidney transplantation. *Am J Kidney Dis*. 2012;59(6):849-857.
5. Waterman AD, Peipert JD, Hyland SS, McCabe MS, Schenk EA, Liu J. Modifiable patient characteristics and racial disparities in evaluation completion and living donor transplant. *Clin J Am Soc Nephrol*. 2013;8(6):995-1002.

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6. Alvaro EM, Siegel JT, Turcotte D, Lisha N, Crano WD, Dominick A. Living kidney donation among Hispanics: a qualitative examination of barriers and opportunities. *Prog Transplant*. 2008;18(4):243-250.
 7. Gordon EJ, Mullee JO, Ramirez DI, et al. Hispanic/Latino concerns about living kidney donation: a focus group study. *Prog Transplant*. 2014;24(2):152-162.
 8. Wachterman MW, McCarthy EP, Marcantonio ER, Ersek M. Mistrust, misperceptions, and miscommunication: a qualitative study of preferences about kidney transplantation among African Americans. *Transplant Proc*. 2015;47(2):240-246.
 9. Johns TS, Estrella MM, Crews DC, et al. Neighborhood socioeconomic status, race, and mortality in young adult dialysis patients. *J Am Soc Nephrol*. 2014;25(11):2649-2657.
 10. Hinck BD, Naelitz BD, Jackson B, Howard M, Nowacki A, Modlin CS. Assessing transplant attitudes: understanding minority men's perspectives on the multifarious barriers to organ donation. *J Racial Ethnic Health Disparities*. 2017;4(4):580-586.
 11. Axelrod DA, Dzebisashvili N, Schnitzler MA, et al. The interplay of socioeconomic status, distance to center, and interdonor service area travel on kidney transplant access and outcomes. *Clin J Am Soc Nephrol*. 2010;5(12):2276-2288.
 12. Herring AA, Woolhandler S, Himmelstein DU. Insurance status of U.S. organ donors and transplant recipients: the uninsured give, but rarely receive. *Int J Health Serv*. 2008;38(4):641-652.
 13. Laurentine KA, Bramstedt KA. Too poor for transplant: finance and insurance issues in transplant ethics. *Prog Transplant*. 2010;20(2):178-185.
 14. McSorley A-MM, Peipert JD, Gonzalez C, et al. Dialysis providers' perceptions of barriers to transplant for black and low-income patients: a mixed methods analysis guided by the socio-ecological model for transplant. *World Med Health Policy*. 2017;9(4):399-416.
 15. Rodrigue JR, LaPointe Rudow D, Hays R; American Society of Transplantation. Living donor kidney transplantation: best practices in live kidney donation—recommendations from a consensus conference. *Clin J Am Soc Nephrol*. 2015;10(9):1656-1657.
 16. Ruck JM, Zhou S, Thomas AG, et al. Electronic messaging and communication with living kidney donors. *Clin Transplant*. 2018;32(2).
 17. Cole-Lewis H, Kershaw T. Text messaging as a tool for behavior change in disease prevention and management. *Epidemiol Rev*. 2010;32(1):56-69.
 18. Wang TC, Huang JL, Ho WC, Chiou AF. Effects of a supportive educational nursing care programme on fatigue and quality of life in patients with heart failure: a randomised controlled trial. *Eur J Cardiovasc Nurs*. 2016;15(2):157-167.
 19. Reilly-Spong M, Reibel D, Pearson T, Koppa P, Gross CR. Telephone-adapted mindfulness-based stress reduction (tMBSR) for patients awaiting kidney transplantation: trial design, rationale and feasibility. *Contemp Clin Trials*. 2015;42:169-184.
 20. Vaiva G, Vaiva G, Ducrocq F, et al. Effect of telephone contact on further suicide attempts in patients discharged from an emergency department: randomised controlled study. *BMJ*. 2006;332(7552):1241-1245.
 21. Waterman AD, McSorley AM, Peipert JD, et al. Explore Transplant at Home: a randomized control trial of an educational intervention to increase transplant knowledge for black and white socioeconomically disadvantaged dialysis patients. *BMC Nephrol*. 2015;16:150.
 22. Waterman AD, Robbins ML, Paiva AL, et al. Measuring kidney patients' motivation to pursue living donor kidney transplant: development of stage of change, decisional balance and self-efficacy measures. *J Health Psychol*. 2015;20(2):210-221.
 23. Waterman AD, Robbins ML, Paiva AL, Hyland SS. Kidney patients' intention to receive a deceased donor transplant: development of stage of change, decisional balance and self-efficacy measures. *J Health Psychol*. 2010;15(3):436-445.
 24. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Ann Intern Med*. 1993;118(8):622-629.
 25. LaVeist TA, Isaac LA, Williams KP. Mistrust of health care organizations is associated with underutilization of health services. *Health Serv Res*. 2009;44(6):2093-2105.
 26. Waterman AD, Peipert JD, Xiao H, et al. Education strategies in dialysis centers associated with increased transplant wait-listing rates. *Transplantation*. 2019. In press.
 27. Rodrigue JR, Paek MJ, Egbuna O, et al. Making house calls increases living donor inquiries and evaluations for blacks on the kidney transplant waiting list. *Transplantation*. 2014;98(9):979-986.
 28. Rodrigue JR, Cornell DL, Lin JK, Kaplan B, Howard RJ. Increasing live donor kidney transplantation: a randomized controlled trial of a home-based educational intervention. *Am J Transplant*. 2007;7(2):394-401.
 29. Boulware LE, Hill-Briggs F, Kraus ES, et al. Effectiveness of educational and social worker interventions to activate patients' discussion and pursuit of preemptive living donor kidney transplantation: a randomized controlled trial. *Am J Kidney Dis*. 2013;61(3):476-486.

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