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Your Path to Transplant: A Randomized Controlled Trial of a Tailored Expert System Intervention to Increase Knowledge, Attitudes and Pursuit of Kidney Transplant

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Abbreviations:

CKD: Chronic kidney disease

DDKT: Deceased donor kidney transplant

ESKD: End-stage kidney disease

KT: Kidney Transplant

LDKT: Living donor kidney transplant

OPTN: Organ Procurement Transplantation Network

RCT: Randomized controlled trial

SOC: Standard of care

UCLA-KPTP: University of California, Los Angeles Kidney and Pancreas Transplant Program

YPT: Your Path to Transplant

ABSTRACT

Individually tailoring education over time may help more patients, especially racial/ethnic minorities, get wait-listed and pursue deceased and living donor kidney transplant (DDKT and LDKT, respectively). We enrolled 802 patients pursuing transplant evaluation at the University of California, Los Angeles Transplant Program into a randomized education trial. We compared the effectiveness of Your Path to Transplant (YPT), an individually tailored coaching and education program delivered at four time points, with standard of care (SOC) education on improving readiness to pursue DDKT and LDKT, transplant knowledge, taking 15 small transplant-related actions, and pursuing transplant (waitlisting or LDKT rates) over 8 months. Survey outcomes were collected prior to evaluation and at 4- and 8-months. Time to waitlisting or LDKT was assessed with at least 18 months of follow-up. At 8 months, compared to SOC, the YPT group demonstrated increased LDKT readiness (47% vs 33%, $p = 0.003$) and transplant knowledge (effect size [ES]=0.41, $p<0.001$). Transplant pursuit was higher in the YPT group (HR: 1.44, 95% CI: 1.15-1.79, $p = 0.002$). A focused, coordinated education effort can improve transplant-seeking behaviors and wait-listing rates.

ClinicalTrials.gov registration: NCT02181114

KEYWORDS

Your Path to Transplant (YPT), computer tailored education, randomized control trial, kidney transplant, living kidney donor transplant education

INTRODUCTION

End-stage kidney disease (ESKD) is becoming the new epidemic of our time (1). Approximately 15% of Americans have chronic kidney disease (CKD), with more than 700,000 people in ESKD, requiring either ongoing dialysis or kidney transplant (KT)(2). Compared to transplant, dialysis is associated with a significantly shorter life expectancy and poorer health-related quality of life (3-5). Living donor kidney transplant (LDKT) is associated with better post-transplant survival rates than deceased donor kidney transplant (DDKT) (6, 7). While the overall number of KTs performed each year increases, LDKTs comprise a declining share of these transplants (7).

Black and Hispanic patients are less likely than White patients to be waitlisted for DDKT or receive LDKTs, even though Black and Hispanic patients have higher rates of ESKD (7). In 2014, while White patients had 11.4% cumulative incidence of LDKT, Black and Hispanic patients only had 2.9% and 5.9% incidence, respectively (8).

Research has identified key modifiable factors that are associated with successful waitlisting, evaluation, and receipt of LDKT. The quality and applicability of education received about transplant and LDKT has been shown in multiple studies to be critical to preparing a patient to pursue KT and LDKT (9, 10). Examining the characteristics of patients who receive LDKTs, multiple studies (11-15) have shown that patients who complete evaluation and receive a LDKT are more likely to have received better education within dialysis centers (16), greater knowledge about transplant, and greater readiness to pursue LDKT (13). Targeted education for patients of racial and ethnic minorities and low socioeconomic status (SES) has also been shown to be beneficial, particularly when the education is culturally sensitive, in their own language, subsidizes transplant costs, and addresses barriers more common to these communities including

low health literacy, transportation challenges, and cultural norms (17-20). However, the impact of educational interventions varies, with some failing to show improvements in knowledge or pursuit of transplant (21, 22).

Best practices for the design of transplant education recommend honoring the patient's stage of readiness for transplant and delivering modular, culturally sensitive, health literate education over longer time periods (10). Computer-tailored interventions (CTIs) have the ability to create tailored feedback based on an individual patient's specific level of readiness, knowledge gaps, self-efficacy challenges, and socioeconomic derailers and detect changes over time (23). In a longitudinal, randomized controlled trial (RCT) at the University of California, Los Angeles Kidney and Pancreas Transplant Program (UCLA-KPTP), we compared the effectiveness of a new CTI for transplant, *Your Path to Transplant* (YPT), with standard of care (SOC) education. We assessed: (1) YPT's effectiveness for improving patients' transplant knowledge, attitudes toward transplant, readiness to pursue transplant, completion of 15 transplant action-steps, and successful pursuit of transplant (waitlisted or LDKT.

METHODS

Randomized Controlled Trial (RCT) Design

This study was a prospective, parallel arm RCT with two follow-up time points conducted among 802 non-Hispanic Black, Hispanic (any race), and non-Hispanic White ESKD patients presenting for transplant evaluation at UCLA-KPTP. Enrolled patients were electronically randomized, stratified by race/ethnicity, with equal allocation to two treatment arms: the YPT intervention and SOC. All patients were surveyed prior to presenting at the transplant center (baseline), and at 4- and 8-months post-baseline.

The study protocol was approved by the University of California, Los Angeles's Institutional Review Board (#14-000382) and registered at ClinicalTrials.gov (#NCT02181114). The full details of the protocol have been published (23).

Setting and Participants

Inclusion criteria for the RCT were: 1) presentation for KT evaluation at UCLA; 2) self-identification as White, Black, or Hispanic (any race). Patients were excluded if they were: 1) under age 18; 2) unable to speak or read English; 3) previously deemed ineligible at UCLA for KT; 4) on the waitlist at another center; 5) pursuing multi-organ transplant; or 6) without a working telephone. Patients were asked to give verbal informed consent to participate and have their electronic medical records reviewed.

Standard of Care (SOC) Arm

The SOC arm consisted of UCLA-KPTP education provided during a 3-hour transplant education session for patients and their family and friends, transplant coordinator communications, and self-study afterwards. The session outlined recipient and donor evaluation, surgery, and recovery processes.

Your Path to Transplant (YPT) Arm

YPT is a computer-tailored intervention that provides patients with telephonic coaching, feedback reports, access to community resources to overcome SES barriers, and video and print KT education resources tailored uniquely to them after a computerized patient assessment. At 4 time points, patients completed a screening to determine their current level of readiness to pursue DDKT and LDKT, transplant knowledge, socioeconomic barriers to transplant, and plan to take specific actions towards pursuing transplant and LDKT. Individual feedback reports were generated by the computer based on this screening that supported a patient at each unique level

of transplant readiness, answered their specific knowledge gaps, and suggested how best to begin taking small transplant actions reported to be of interest to the patient. Patients were also provided referrals to community resources that might overcome SES barriers that might derail patients from transplantation, videos and print brochures from the Explore Transplant education program (24). Coaches emphasized the content and recommendations generated within the report and brainstormed with the patient on any transplant actions of interest to them and SES barriers identified. Each new screening at different time points updated the computerized patient assessment and generated a new tailored report. YPT patients received educational resources and coaching at 4 time points: a few weeks before and during transplant evaluation, and 4 and 8 months after baseline (Figure 1). Across all these time points, YPT patients received approximately 75 additional minutes of education compared to the SOC patients over an 8-month period. The YPT-generated coaching was delivered in person during evaluation and by telephone by a diverse racial/ethnic group of trained social work and public health coaches overseen by a clinical psychologist. Coaches were not matched by race/ethnicity to the patients they were coaching.

Measures

The primary study outcome was patients' readiness to pursue LDKT and DDKT. To assess transplant readiness, patients were asked how ready they were to get a DDKT or LDKT and were scored as being in one of five stages (e.g., precontemplation, contemplation, preparation, action, maintenance) using our validated DDKT and LDKT stage of readiness measurement tools (25, 26) (Table 1). To assess transplant knowledge patients were asked 11 true/false and 8 multiple choice questions to determine their level of knowledge (14), producing a knowledge T-score (mean=50, SD=10) (15), with higher scores indicating greater knowledge.

To assess ongoing progress toward transplant, patients were asked whether they had "Already done," "Are planning to do," or "Don't plan to do" 15 transplant-related action-steps (25, 26). Examples of action-steps included "Share educational materials about deceased donation with people in your life" or "Ask potential donors to be tested." Patients who said they had not "Already done" the action at baseline but had done so at a later survey time point were counted as having newly taken that step, with the total number of new steps taken calculated. Finally, pursuit of transplant (i.e., waitlisted for DDKT or received LDKT) was assessed via medical record review and linkage to the Scientific Registry for Transplant Recipients (SRTR) 18 months after enrollment of the last patient.

Additionally, the pre-intervention survey assessed basic patient demographic and clinical characteristics and level of SES barriers using the Kidney Transplant Derailers Index (KTDI)(27). We also asked patients whether they had previously read transplant brochures, watched transplant videos, or visited transplant websites.

Statistical Analyses

Details of the power analysis and rationale for the patient sample size recruited for this RCT have been published (23). All statistical tests employ an intent-to-treat (ITT) approach wherein subjects maintain their assignment to the study arm to which they were originally randomized regardless of whether they completed the planned interventions (28). To compare baseline characteristics between patients who dropped out of the study to those who did not, independent samples *t*-tests or nonparametric Kruskal-Wallis tests were used for continuous variables and chi-square or Fisher's exact tests were used for categorical variables.

To evaluate differences between groups on the primary endpoint, DDKT and LDKT readiness levels were each first collapsed to a binary classification of Action versus all earlier

stages of readiness. This binary outcome was then assessed in a mixed effect logistic regression model using R package lme4 (29). Maximum likelihood-based mixed effects models use all available data for each patient and provide valid estimates under the assumption that missing data are missing at random, conditional on the observed data. Intervention group, time, and the interaction between group and time were included in the model as fixed effects, along with random intercept and slope (time) terms at the patient level. The interaction between group and time represents the primary test of whether the changes in readiness over time differ between the two groups.

For the secondary endpoints, to test whether YPT patients showed increased knowledge scores compared to the SOC, a linear mixed effect model was fit using similar specifications of fixed and random effects as the model used for readiness. Effect sizes (ES = mean difference / baseline standard deviation) were calculated to provide a standardized, unitless measure of the magnitude of differences, which can be interpreted with the following cut-offs: $0.20 \leq ES < 0.50$ = small; $0.50 \leq ES < 0.80$ = medium; ≥ 0.80 = large. For the number of new steps taken, differences between the study arms in the count of new steps was analyzed with a Poisson model.

Pursuit of transplant was analyzed as time to event, defined as being placed on the deceased donor waiting list or receiving a LDKT. The time (in months) was calculated between the baseline survey date and date listed in SRTR, or date that patient received an LDKT. Patients who were not listed or transplanted were censored on November 30, 2018—18 months after the last patient was enrolled in the study. We also examined time to LDKT, specifically. Kaplan-Meier curves were stratified by study arm and differences assessed using the log-rank test. Cox proportional hazards models, adjusted for the randomization stratification factor – race/ethnicity,

were also fit and hazards ratios estimated. The proportional hazards assumption was evaluated using statistical tests and graphical diagnostics based on the scaled Schoenfeld residuals.

Since this study was powered only to detect a main effect of intervention, interaction tests by race/ethnicity are considered exploratory. No adjustments for multiple comparisons were applied. All analyses were conducted in R version 3.5.1 (R Core Team)(30) and SAS version 9.4 (Cary, NC).

RESULTS

Participants

Study enrollment took place from May 2014 to May 2017, with follow-up for final pursuit of transplant outcomes through November 2018. Compared to those who consented (33%), those who declined participation were more likely to be Hispanic (Table S1). Of the 802 eligible patients who completed the baseline survey, 407 were allocated to the YPT group and 395 to the SOC group. Characteristics of the sample are listed in Table 2. Before joining the study, most participants read transplant brochures (62.8%), browsed websites about transplant (53.5%), or talked to doctors and other medical staff about transplant (87.4%), but few had watched videos about transplant (26.8%).

A CONSORT diagram with reasons for drop-out at each time point is displayed in Figure 2. Patients who completed the 8-month survey were more likely to be in the SOC arm (p=0.009), have polycystic kidney disease as their etiology for ESKD (p = 0.016), and not yet be on dialysis (p = 0.013). There were no differences in study drop-out between race/ethnicity groups (Tables S2-S3).

Primary Outcome: Transplant Readiness

At baseline, 67.5% of patients reported being in the Action stage of readiness for DDKT and 44.5% in the Action stage for LDKT. Significantly higher proportions of YPT patients reported being in Action for DDKT compared to the SOC group at 4 months (82.8% vs. 72.5%, p = 0.004), but this difference was not as large at 8 months (84.0% vs. 76.4.0%, p = 0.066). In the mixed effects longitudinal model, the odds ratio [OR] for the comparison at 8 months was 3.16 (95% confidence interval [CI]: 0.92, 5.39; p-value = 0.019). A higher proportion of YPT patients reported being in Action for LDKT compared to SOC patients at 4 months (59.3% vs. 50.2%, p = 0.036), with a larger difference at 8 months (67.0% vs. 44.1%, p< 0.001; mixed model OR: 3.77, 95% CI: 1.04, 6.50; p = 0.005). The effect of YPT on LDKT readiness differed by race/ethnicity in the model (interaction p=0.039). However, this interaction between treatment and race/ethnicity was not observed for DDKT readiness (interaction p=0.087).

Secondary Outcome: Transplant Knowledge

At baseline, mean transplant knowledge T-score was 52.1 (SD=9.7). Compared to the SOC arm, a larger increase in transplant knowledge was observed for the YPT group over time (Figure 3; interaction p < 0.001). The difference between YPT and SOC was 1.5 points (ES = 0.15, p = 0.082) at 4 months and 4.1 points (ES = 0.42, p < 0.001) at 8 months. Race did not interact with treatment, indicating the effect of study arm on transplant knowledge after baseline did not differ substantially by race/ethnicity group (interaction p=0.70).

Secondary Outcome: New Steps toward LDKT and DDKT

At baseline, patients had taken a median of 1.0 steps towards LDKT (IQR = 4.0) and 2.0 steps towards DDKT (SD=3.0). Overall, the most common steps already taken at baseline were calling the transplant center to pursue evaluation, talking to people they trust about whether to get a living donor transplant, and making a list of people who might be living donors.

By the end of the study, YPT patients had taken a median of 3.0 (IQR = 3.0) new steps towards LDKT, compared to a median of 2.0 (IQR = 3.0) new steps in the SOC arm (RR: 1.12, 95% CI: 1.01 - 1.24, p=0.034). In addition to total new steps taken, YPT patients were more likely to take almost every individual new step towards LDKT and DDKT in comparison with the SOC arm (Table 3). Specifically, more YPT patients shared their need for a living donor with a large community (43.6% vs. 27.1%, p=0.001), shared educational materials about living donation with others in their life (86.0% vs. 67.0%, p<0.001), asked another person to tell others of their need for a living donor (63.8% vs. 49.3%, p=0.009), and asked potential donors to be tested (70.7% vs. 53.7%).

There was also a significant difference between groups in number of new steps taken towards DDKT (RR = 1.13, 95% CI: 1.05 – 1.22, p=0.002) with a median of 5.0 (IQR = 3.0) new steps taken for the YPT arm and 4.0 (IQR = 3.0) for the SOC arm. More YPT patients shared educational materials about DDKT with people in their life (87.9% vs. 67.3%, p<0.001) and talked to people they trust about whether to get a DDKT (87.2% vs. 67.6%, p<0.001). No heterogeneity of intervention effect was observed for race (interaction p=0.67).

Final Outcome – Transplant Pursuit

After a minimum of 18 months follow-up, 323 patients total (40.2%) were either waitlisted for DDKT or received a LDKT (57.0% YPT vs 43.0% SOC), with those receiving the YPT intervention faring better (Figure 4, log-rank p = 0.003; HR: 1.39, 95% CI: 1.12 – 1.74). This benefit was unchanged after adjusting for race/ethnicity (HR: 1.44, 95% CI: 1.15 - 1.79; p = 0.002). No statistically significant interaction was observed between race/ethnicity and intervention group (p>0.2).

During the same follow-up period, 95 patients (11.8%) received an LDKT, with 53 (13.0%) in the YPT condition and 42 (10.6%) in the SOC condition (Figure 5, log-rank p = 0.42). There was no evidence that the YPT intervention had an effect on LDKT rates (HR: 1.23, 95% CI: 0.81 – 1.85; p=0.329). No interaction was observed between race/ethnicity and intervention groups in receipt of LDKT (interaction p=0.943).

Evaluation of YPT. Over 95% of participants found the coaches and print materials helpful and easy to understand. There was no difference between race/ethnicity groups in evaluation ratings.

DISCUSSION

For patients presenting for transplant evaluation, the road to successful kidney transplantation can be long and challenging. A recent study found that the average time to complete evaluation and get waitlisted was 226 days (31). This is the first examination of the effectiveness of an individually tailored education and coaching program, *Your Path to Transplant,* being delivered over 8 months during pursuit of evaluation. This study found that kidney patients who received YPT were more likely to increase their transplant knowledge, increase their readiness to pursue DDKT and LDKT, take more steps toward DDKT and LDKT, and be listed for transplant than patients who received only traditional SOC education. While YPT patients also were more likely to share their interest with people about LDKT and solicit living donors, there were no differences in actual LDKT rates by education condition after 18 months.

This is one of the longest and most comprehensive educational interventions ever to occur within a transplant center. While similar transplant educational studies vary in duration from one day to 18 months (17, 22, 24, 32-34), most commonly, they involve interventions

occurring on evaluation day or during a single clinical visit with supplemental information provided afterwards for additional self-study (35, 36). Multiple studies now support expanding the length of interventions, involving living donors, and including multiple resources within interventions like videos, print materials, and coaching (17, 24, 32).

As part of their conversations, YPT coaches spent considerable time attempting to overcome commonly reported SES barriers to transplant (17-19). For example, during the coaching sessions, they provided information about low-cost or free transportation to the transplant center, dental care, and child care services, and discussed practical topics like where to park at the center and which bus route would help patients most easily get to the transplant center. Similarly, Basu et al., found that 4% of patient navigator encounters addressed transportation challenges (37).

In examining other interventions shown to increase transplant-seeking behaviors in racial/ethnic minorities, patient-level interventions using patient navigators (37, 38), home-based education with a minority health educator (17, 39), culturally targeted websites (33, 40), and culturally congruent transplant programs (41) have been found to be effective. At the patient and family level, discussions between participants and social workers (36), web-based education (33, 42), home-based educational meetings with patients (43), and meetings using technology to seek donors (44), and involving a patient's social network, including potential living donors (45) have proven effectiveness. At the provider and system level, research has found that transplant facilities with specifically tailored toolkits to coordinate patient care (46, 47), and risk-based approaches identifying patients in need of targeted care (48, 49) were more successful. Interventions including multiple levels of the socioecological model may be needed, perhaps in combination (50-52).

Finally, this study has several limitations. First, the RCT was conducted in a single, high-volume transplant center in an urban area and, thus, may be limited in generalizability. Selection bias also potentially threatens generalizability of the study, as 21.6% (536 out of 2483) of pre-randomized patients declined to participate in the study, with a lower proportion of Hispanic patients providing consent. Over time, nearly 20% of patients could not complete all time points because they either died or became ineligible for transplant. Of the 80% that remained eligible for transplant over the entire 8- month time period, 36% were lost to follow-up by the 8-month visit, with a higher drop-out rate in the YPT group compared to SOC, potentially biasing our conclusions. If all patients still eligible for transplant but lost to follow-up were considered to be "not taking actions" towards LDKT, we find that patients in the YPT arm were still more likely to be taking actions than SOC (YPT: 130/325=40% vs SOC: 101/325=31%, p=0.017). Finally, it is possible that some of YPT's treatment effect was diluted by patients who did not read the tailored education reports or watch the videos on their own at home. Since telephonic coaching sessions reviewed the content from these materials, even patients using the materials on their own but less often would still have some exposure to the intervention.

YPT provides an innovative option for supporting a racially and ethnically diverse ESKD patient population facing the many challenges of transplant evaluation and finding a living donor. This study revealed that it is possible to improve transplant patients' knowledge, pursuit of transplant, and wait-listing rates if a focused, coordinated education effort honoring patients' readiness and motivation to pursue DDKT and LDKT, addressing their unique SES barriers, and supporting them in taking critical transplant actions over time can be implemented. These individually tailored strategies could be embedded within traditional education programs at transplant centers to meet patients' educational needs.

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Disclosure

Dr. Amy D. Waterman, PhD owns the intellectual property to the transplant education product *Explore Transplant* and has licensed it at no-cost to a nonprofit, Health Literacy Media (HLM), who retains all revenue as to their sales. She serves as an unpaid consultant to HLM to ensure the accuracy of educational content. All other authors declare that they have no competing interests.

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Table 1: DDKT and LDKT Stages of Readiness Measurement

DDKT Survey Question	**Stage of Readiness**
I am not considering getting a DDKT in the next six months	Precontemplation
I am considering getting a DDKT in the next six months	Contemplation
I am preparing to get a DDKT in the next 30 days	Preparation
I am undergoing evaluation to get a DDKT	Action
I am listed and waiting to get a DDKT	Maintenance

LDKT Survey Question	**Stage of Readiness**
I am not considering taking actions in the next six months to pursue LDKT	Precontemplation
I am considering taking actions in the next 30 days to pursue LDKT	Contemplation
I am preparing to take actions in the next 30 days to pursue LDKT	Preparation
I am taking actions to pursue LDKT	Action

Table 2. Baseline patient characteristics overall and by randomized group

	Overall (N=802)	YPT (N= 407)	SOC (N= 395)
Age, mean (SD)	53.0 (13.1)	52.7 (13.0)	53.2 (13.3)
Sex, n (%)			
Men	486 (60.6)	239 (58.7)	247 (62.5)
Women	316 (39.4)	168 (41.3)	148 (37.5)
Race/ethnicity, n (%)			
Non-Hispanic Black	200 (24.9)	108 (26.5)	92 (23.3)
Hispanic	313 (39.0)	155 (38.0)	158 (40.0)
Non-Hispanic White	279 (34.7)	138 (33.8)	141 (35.7)
Other	11 (1.4)	7 (1.7)	4 (1.0)
Comorbidities, n (%)			
Diabetes	350 (43.6)	157 (38.6)	193 (48.9)
Hypertension	661 (82.4)	337 (82.8)	324 (82.0)
Polycystic kidney disease	89 (11.1)	44 (10.8)	45 (11.4)
Insurance, n (%)			
Medicare	122 (15.3)	56 (13.9)	66 (16.8)
Medicaid	221 (27.7)	119 (29.5)	102 (26.0)
Private Insurance (i.e. HMO, PPO)	427 (53.6)	221 (54.7)	206 (52.4)
Don't know	7 (0.9)	2 (0.5)	5 (1.3)
Other insurance	20 (2.5)	6 (1.5)	14 (3.6)
On dialysis, n (%)	560 (69.8)	275 (67.6)	285 (72.2)
Education, n (%)			
8th grade or less	19 (2.4)	6 (1.5)	13 (3.3)
Some high school	56 (7.0)	23 (5.7)	33 (8.4)
High School Diploma or GED	197 (24.6)	101 (24.8)	96 (24.3)
Some college or vocational school	253 (31.6)	129 (31.7)	124 (31.4)
College or vocational school degree	182 (22.7)	100 (24.6)	82 (20.8)
Some professional or graduate school	21 (2.6)	10 (2.5)	11 (2.8)
Professional or graduate degree	74 (9.2)	38 (9.3)	36 (9.1)
Transplant Education, n (%)			
Read brochures about transplants	504 (62.8)	258 (63.4)	246 (62.3)
Watched videos	215 (26.8)	111 (27.3)	104 (26.3)
Browsed Internet websites	429 (53.5)	222 (54.5)	207 (52.4)
Talked to doctors and other medical staff	701 (87.4)	357 (87.7)	344 (87.1)

Table 3. New steps towards LDKT and DDKT over the 8-month study period by randomized group

	Total N*	YPT N (%)	SOC N (%)	p-value
Steps toward LDKT				
Share education materials about living donation with people in your life	342	135 (86.0%)	124 (67.0%)	<0.001
Generally, talk to people you trust about whether to get a living donor transplant	270	109 (86.5%)	108 (75.0%)	0.026
Make a list of people who might be a living donor for you	280	87 (70.7%)	93 (59.2%)	0.062
Ask another person to tell others about your need for a living donor transplant	353	97 (63.8%)	99 (49.3%)	0.009
Ask potential donors to be tested	358	111 (70.7%)	108 (53.7%)	0.002
Give potential living donors the transplant center phone number	417	134 (69.4%)	129 (57.6%)	0.017
Share my need for a living donor with a large community (e.g., Facebook, Twitter, etc.)?	397	78 (43.6%)	59 (27.1%)	0.001
Steps toward DDKT				
Read information/watch videos about getting on the deceased donor waiting list	419	179 (88.6%)	157 (72.4%)	<0.001
Share educational materials about deceased donation with people in your life	387	160 (87.9%)	138 (67.3%)	<0.001
Generally, talk to people you trust about whether to get a deceased donor transplant	348	150 (87.2%)	119 (67.6%)	<0.001
Call the transplant center to pursue evaluation	219	97 (93.3%)	101 (87.8%)	0.256
Complete and mail back the transplant center's new patient medical forms	451	208 (95.9%)	207 (88.5%)	0.007
Invite someone to come to evaluation with you	286	125 (94.7%)	135 (87.7%)	0.063
Come to the transplant center to complete medical tests	499	232 (93.5%)	206 (82.1%)	<0.001
Follow-up with transplant coordinator until transplant evaluation is complete	462	178 (79.1%)	162 (68.4%)	0.012

*Total sample size not already doing step at baseline.

Figure 1. Study design

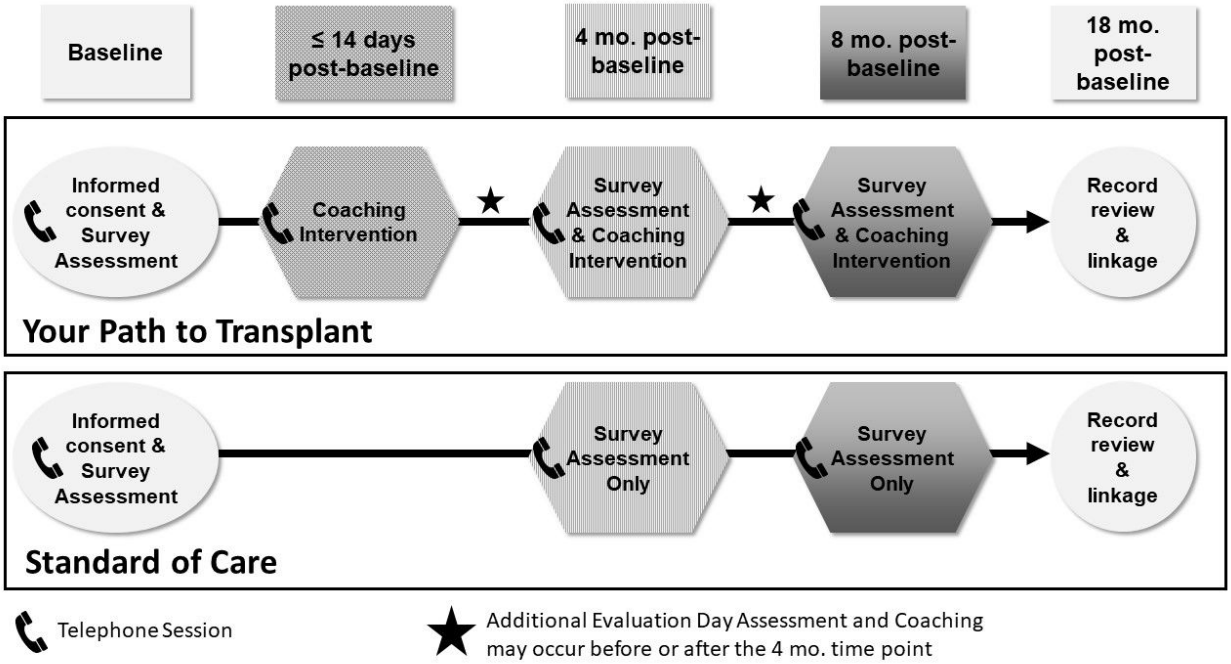


Figure 2. Your Path to Transplant Trial CONSORT Flowchart

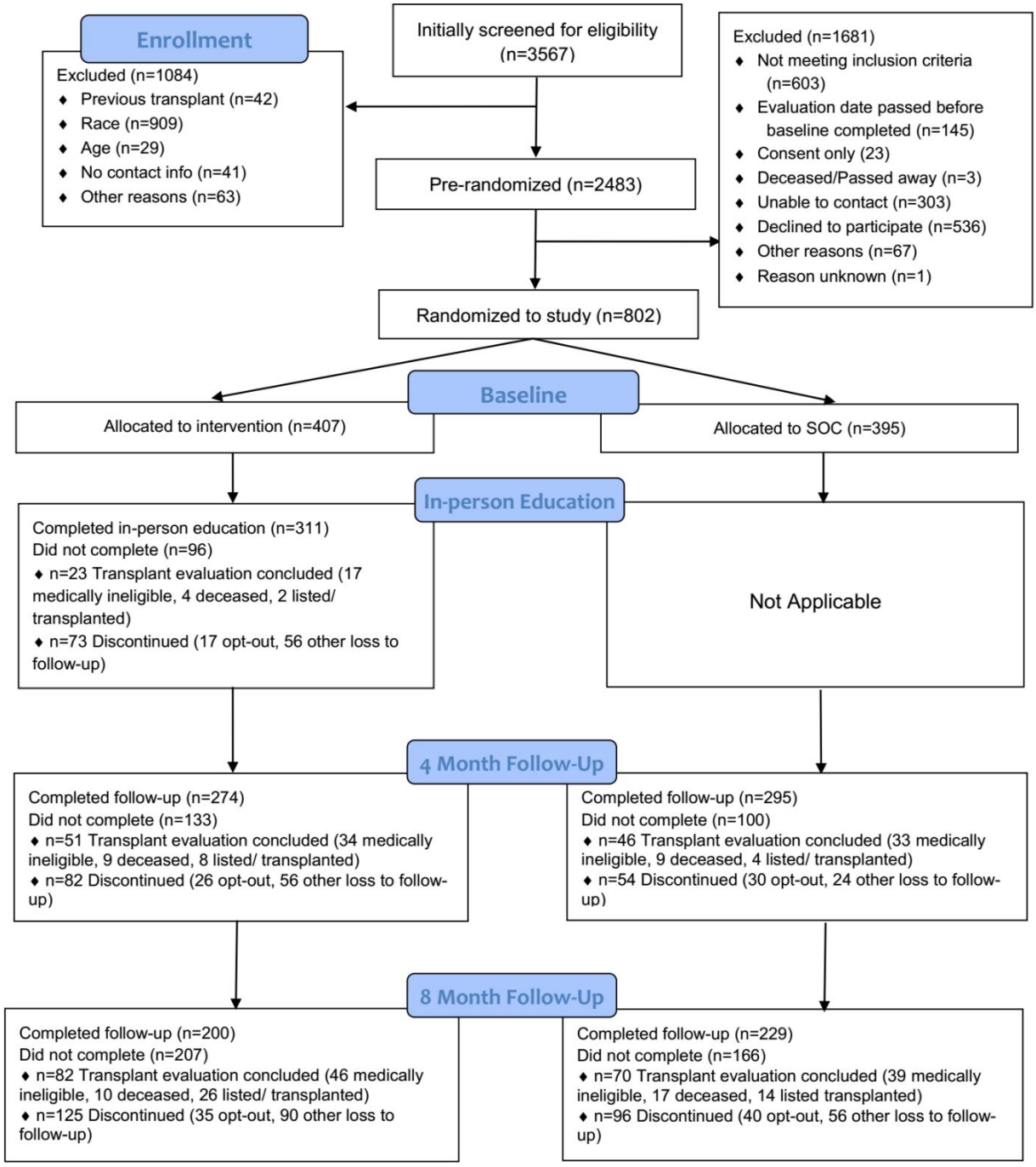
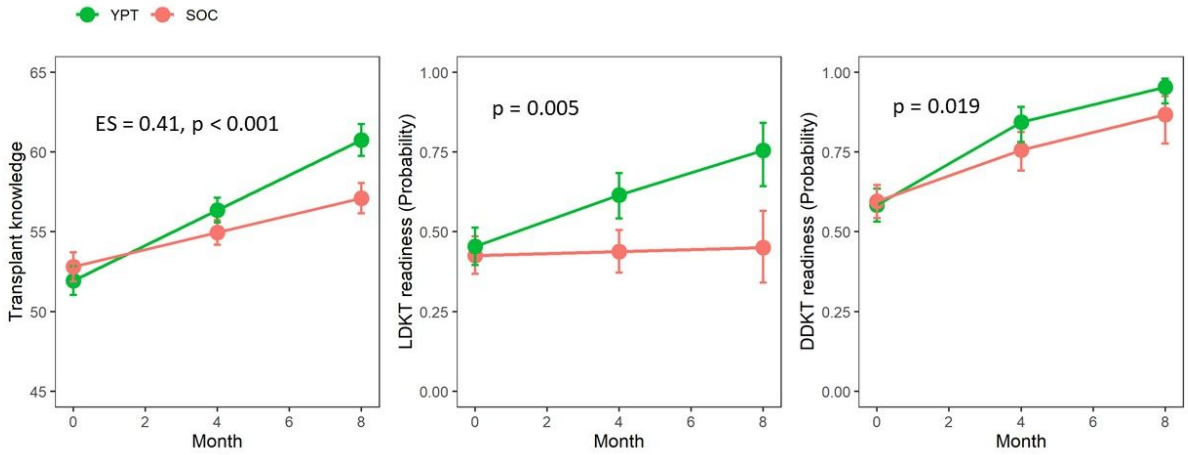


Figure 3. Transplant knowledge and readiness over time (mixed effect model predicted means and 95% confidence intervals)



Effect size and p-values are for comparison between YPT and SOC at month 8.

Figure 4: Waitlisting rate by randomized group

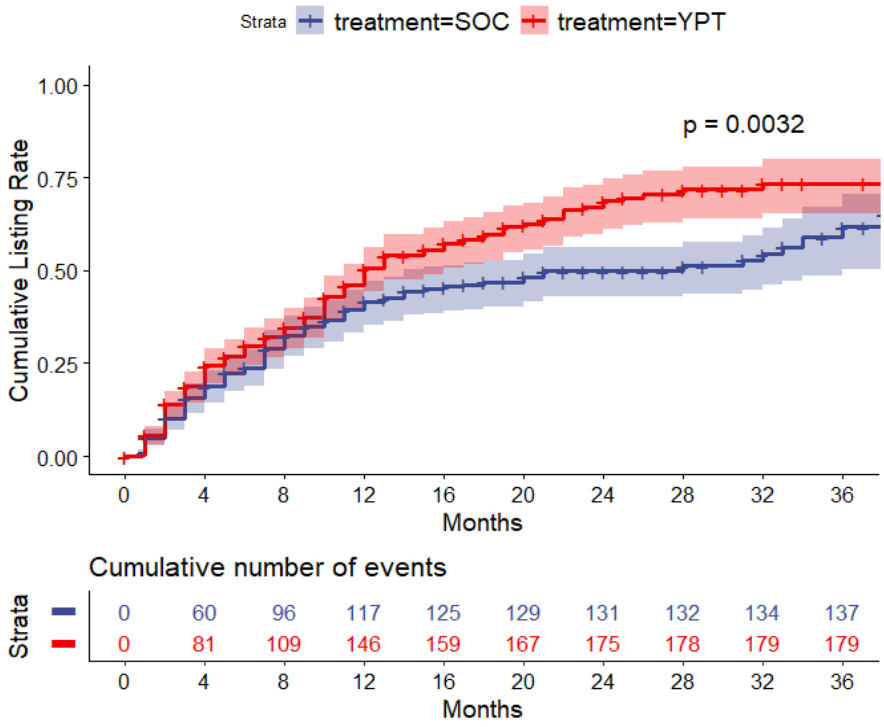
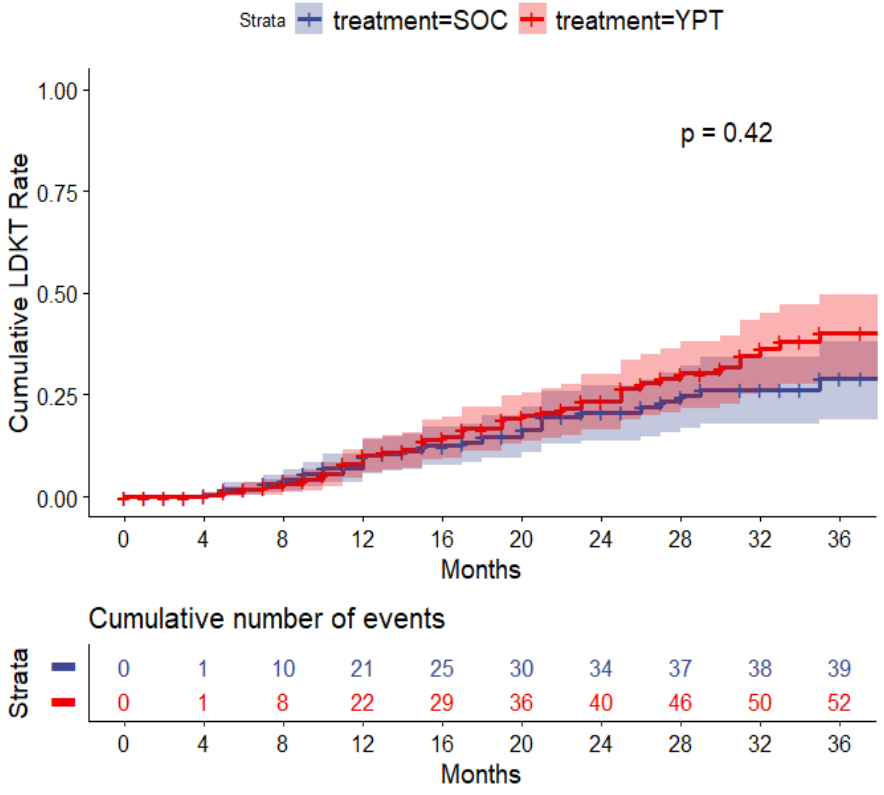


Figure 5: LDKT rate by randomized group



Your Path to Transplant: A Randomized Controlled Trial of a Tailored Expert System Intervention to Increase Knowledge, Attitudes and Pursuit of Kidney Transplant

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Abbreviations:

CKD: Chronic kidney disease

DDKT: Deceased donor kidney transplant

ESKD: End-stage kidney disease

KT: Kidney Transplant

LDKT: Living donor kidney transplant

OPTN: Organ Procurement Transplantation Network

RCT: Randomized controlled trial

SOC: Standard of care

UCLA-KPTP: University of California, Los Angeles Kidney and Pancreas Transplant Program

YPT: Your Path to Transplant

ABSTRACT

Individually tailoring education over time may help more patients, especially racial/ethnic minorities, get wait-listed and pursue deceased and living donor kidney transplant (DDKT and LDKT, respectively). We enrolled 802 patients pursuing transplant evaluation at the University of California, Los Angeles Transplant Program into a randomized education trial. We compared the effectiveness of Your Path to Transplant (YPT), an individually tailored coaching and education program delivered at four time points, with standard of care (SOC) education on improving readiness to pursue DDKT and LDKT, transplant knowledge, taking 15 small transplant-related actions, and pursuing transplant (waitlisting or LDKT rates) over 8 months. Survey outcomes were collected prior to evaluation and at 4- and 8-months. Time to waitlisting or LDKT was assessed with at least 18 months of follow-up. At 8 months, compared to SOC, the YPT group demonstrated increased LDKT readiness (47% vs 33%, $p = 0.003$) and transplant knowledge (effect size [ES]=0.41, $p<0.001$). Transplant pursuit was higher in the YPT group (HR: 1.44, 95% CI: 1.15-1.79, $p = 0.002$). A focused, coordinated education effort can improve transplant-seeking behaviors and wait-listing rates.

ClinicalTrials.gov registration: NCT02181114

KEYWORDS

Your Path to Transplant (YPT), computer tailored education, randomized control trial, kidney transplant, living kidney donor transplant education

INTRODUCTION

End-stage kidney disease (ESKD) is becoming the new epidemic of our time (1). Approximately 15% of Americans have chronic kidney disease (CKD), with more than 700,000 people in ESKD, requiring either ongoing dialysis or kidney transplant (KT)(2). Compared to transplant, dialysis is associated with a significantly shorter life expectancy and poorer health-related quality of life (3-5). Living donor kidney transplant (LDKT) is associated with better post-transplant survival rates than deceased donor kidney transplant (DDKT) (6, 7). While the overall number of KTs performed each year increases, LDKTs comprise a declining share of these transplants (7).

Black and Hispanic patients are less likely than White patients to be waitlisted for DDKT or receive LDKTs, even though Black and Hispanic patients have higher rates of ESKD (7). In 2014, while White patients had 11.4% cumulative incidence of LDKT, Black and Hispanic patients only had 2.9% and 5.9% incidence, respectively (8).

Research has identified key modifiable factors that are associated with successful waitlisting, evaluation, and receipt of LDKT. The quality and applicability of education received about transplant and LDKT has been shown in multiple studies to be critical to preparing a patient to pursue KT and LDKT (9, 10). Examining the characteristics of patients who receive LDKTs, multiple studies (11-15) have shown that patients who complete evaluation and receive a LDKT are more likely to have received better education within dialysis centers (16), greater knowledge about transplant, and greater readiness to pursue LDKT (13). Targeted education for patients of racial and ethnic minorities and low socioeconomic status (SES) has also been shown to be beneficial, particularly when the education is culturally sensitive, in their own language, subsidizes transplant costs, and addresses barriers more common to these communities including

low health literacy, transportation challenges, and cultural norms (17-20). However, the impact of educational interventions varies, with some failing to show improvements in knowledge or pursuit of transplant (21, 22).

Best practices for the design of transplant education recommend honoring the patient's stage of readiness for transplant and delivering modular, culturally sensitive, health literate education over longer time periods (10). Computer-tailored interventions (CTIs) have the ability to create tailored feedback based on an individual patient's specific level of readiness, knowledge gaps, self-efficacy challenges, and socioeconomic derailers and detect changes over time (23). In a longitudinal, randomized controlled trial (RCT) at the University of California, Los Angeles Kidney and Pancreas Transplant Program (UCLA-KPTP), we compared the effectiveness of a new CTI for transplant, *Your Path to Transplant* (YPT), with standard of care (SOC) education. We assessed: (1) YPT's effectiveness for improving patients' transplant knowledge, attitudes toward transplant, readiness to pursue transplant, completion of 15 transplant action-steps, and successful pursuit of transplant (waitlisted or LDKT.

METHODS

Randomized Controlled Trial (RCT) Design

This study was a prospective, parallel arm RCT with two follow-up time points conducted among 802 non-Hispanic Black, Hispanic (any race), and non-Hispanic White ESKD patients presenting for transplant evaluation at UCLA-KPTP. Enrolled patients were electronically randomized, stratified by race/ethnicity, with equal allocation to two treatment arms: the YPT intervention and SOC. All patients were surveyed prior to presenting at the transplant center (baseline), and at 4- and 8-months post-baseline.

The study protocol was approved by the University of California, Los Angeles's Institutional Review Board (#14-000382) and registered at ClinicalTrials.gov (#NCT02181114). The full details of the protocol have been published (23).

Setting and Participants

Inclusion criteria for the RCT were: 1) presentation for KT evaluation at UCLA; 2) self-identification as White, Black, or Hispanic (any race). Patients were excluded if they were: 1) under age 18; 2) unable to speak or read English; 3) previously deemed ineligible at UCLA for KT; 4) on the waitlist at another center; 5) pursuing multi-organ transplant; or 6) without a working telephone. Patients were asked to give verbal informed consent to participate and have their electronic medical records reviewed.

Standard of Care (SOC) Arm

The SOC arm consisted of UCLA-KPTP education provided during a 3-hour transplant education session for patients and their family and friends, transplant coordinator communications, and self-study afterwards. The session outlined recipient and donor evaluation, surgery, and recovery processes.

Your Path to Transplant (YPT) Arm

YPT is a computer-tailored intervention that provides patients with telephonic coaching, feedback reports, access to community resources to overcome SES barriers, and video and print KT education resources tailored uniquely to them after a computerized patient assessment. At 4 time points, patients completed a screening to determine their current level of readiness to pursue DDKT and LDKT, transplant knowledge, socioeconomic barriers to transplant, and plan to take specific actions towards pursuing transplant and LDKT. Individual feedback reports were generated by the computer based on this screening that supported a patient at each unique level

of transplant readiness, answered their specific knowledge gaps, and suggested how best to begin taking small transplant actions reported to be of interest to the patient. Patients were also provided referrals to community resources that might overcome SES barriers that might derail patients from transplantation, videos and print brochures from the Explore Transplant education program (24). Coaches emphasized the content and recommendations generated within the report and brainstormed with the patient on any transplant actions of interest to them and SES barriers identified. Each new screening at different time points updated the computerized patient assessment and generated a new tailored report. YPT patients received educational resources and coaching at 4 time points: a few weeks before and during transplant evaluation, and 4 and 8 months after baseline (Figure 1). Across all these time points, YPT patients received approximately 75 additional minutes of education compared to the SOC patients over an 8-month period. The YPT-generated coaching was delivered in person during evaluation and by telephone by a diverse racial/ethnic group of trained social work and public health coaches overseen by a clinical psychologist. Coaches were not matched by race/ethnicity to the patients they were coaching.

Measures

The primary study outcome was patients' readiness to pursue LDKT and DDKT. To assess transplant readiness, patients were asked how ready they were to get a DDKT or LDKT and were scored as being in one of five stages (e.g., precontemplation, contemplation, preparation, action, maintenance) using our validated DDKT and LDKT stage of readiness measurement tools (25, 26) (Table 1). To assess transplant knowledge patients were asked 11 true/false and 8 multiple choice questions to determine their level of knowledge (14), producing a knowledge T-score (mean=50, SD=10) (15), with higher scores indicating greater knowledge.

To assess ongoing progress toward transplant, patients were asked whether they had "Already done," "Are planning to do," or "Don't plan to do" 15 transplant-related action-steps (25, 26). Examples of action-steps included "Share educational materials about deceased donation with people in your life" or "Ask potential donors to be tested." Patients who said they had not "Already done" the action at baseline but had done so at a later survey time point were counted as having newly taken that step, with the total number of new steps taken calculated. Finally, pursuit of transplant (i.e., waitlisted for DDKT or received LDKT) was assessed via medical record review and linkage to the Scientific Registry for Transplant Recipients (SRTR) 18 months after enrollment of the last patient.

Additionally, the pre-intervention survey assessed basic patient demographic and clinical characteristics and level of SES barriers using the Kidney Transplant Derailers Index (KTDI)(27). We also asked patients whether they had previously read transplant brochures, watched transplant videos, or visited transplant websites.

Statistical Analyses

Details of the power analysis and rationale for the patient sample size recruited for this RCT have been published (23). All statistical tests employ an intent-to-treat (ITT) approach wherein subjects maintain their assignment to the study arm to which they were originally randomized regardless of whether they completed the planned interventions (28). To compare baseline characteristics between patients who dropped out of the study to those who did not, independent samples *t*-tests or nonparametric Kruskal-Wallis tests were used for continuous variables and chi-square or Fisher's exact tests were used for categorical variables.

To evaluate differences between groups on the primary endpoint, DDKT and LDKT readiness levels were each first collapsed to a binary classification of Action versus all earlier

stages of readiness. This binary outcome was then assessed in a mixed effect logistic regression model using R package lme4 (29). Maximum likelihood-based mixed effects models use all available data for each patient and provide valid estimates under the assumption that missing data are missing at random, conditional on the observed data. Intervention group, time, and the interaction between group and time were included in the model as fixed effects, along with random intercept and slope (time) terms at the patient level. The interaction between group and time represents the primary test of whether the changes in readiness over time differ between the two groups.

For the secondary endpoints, to test whether YPT patients showed increased knowledge scores compared to the SOC, a linear mixed effect model was fit using similar specifications of fixed and random effects as the model used for readiness. Effect sizes (ES = mean difference / baseline standard deviation) were calculated to provide a standardized, unitless measure of the magnitude of differences, which can be interpreted with the following cut-offs: $0.20 \leq ES < 0.50$ = small; $0.50 \leq ES < 0.80$ = medium; ≥ 0.80 = large. For the number of new steps taken, differences between the study arms in the count of new steps was analyzed with a Poisson model.

Pursuit of transplant was analyzed as time to event, defined as being placed on the deceased donor waiting list or receiving a LDKT. The time (in months) was calculated between the baseline survey date and date listed in SRTR, or date that patient received an LDKT. Patients who were not listed or transplanted were censored on November 30, 2018—18 months after the last patient was enrolled in the study. We also examined time to LDKT, specifically. Kaplan-Meier curves were stratified by study arm and differences assessed using the log-rank test. Cox proportional hazards models, adjusted for the randomization stratification factor – race/ethnicity,

were also fit and hazards ratios estimated. The proportional hazards assumption was evaluated using statistical tests and graphical diagnostics based on the scaled Schoenfeld residuals.

Since this study was powered only to detect a main effect of intervention, interaction tests by race/ethnicity are considered exploratory. No adjustments for multiple comparisons were applied. All analyses were conducted in R version 3.5.1 (R Core Team)(30) and SAS version 9.4 (Cary, NC).

RESULTS

Participants

Study enrollment took place from May 2014 to May 2017, with follow-up for final pursuit of transplant outcomes through November 2018. Compared to those who consented (33%), those who declined participation were more likely to be Hispanic (Table S1). Of the 802 eligible patients who completed the baseline survey, 407 were allocated to the YPT group and 395 to the SOC group. Characteristics of the sample are listed in Table 2. Before joining the study, most participants read transplant brochures (62.8%), browsed websites about transplant (53.5%), or talked to doctors and other medical staff about transplant (87.4%), but few had watched videos about transplant (26.8%).

A CONSORT diagram with reasons for drop-out at each time point is displayed in Figure 2. Patients who completed the 8-month survey were more likely to be in the SOC arm (p=0.009), have polycystic kidney disease as their etiology for ESKD (p = 0.016), and not yet be on dialysis (p = 0.013). There were no differences in study drop-out between race/ethnicity groups (Tables S2-S3).

Primary Outcome: Transplant Readiness

At baseline, 67.5% of patients reported being in the Action stage of readiness for DDKT and 44.5% in the Action stage for LDKT. Significantly higher proportions of YPT patients reported being in Action for DDKT compared to the SOC group at 4 months (82.8% vs. 72.5%, p = 0.004), but this difference was not as large at 8 months (84.0% vs. 76.4.0%, p = 0.066). In the mixed effects longitudinal model, the odds ratio [OR] for the comparison at 8 months was 3.16 (95% confidence interval [CI]: 0.92, 5.39; p-value = 0.019). A higher proportion of YPT patients reported being in Action for LDKT compared to SOC patients at 4 months (59.3% vs. 50.2%, p = 0.036), with a larger difference at 8 months (67.0% vs. 44.1%, p< 0.001; mixed model OR: 3.77, 95% CI: 1.04, 6.50; p = 0.005). The effect of YPT on LDKT readiness differed by race/ethnicity in the model (interaction p=0.039). However, this interaction between treatment and race/ethnicity was not observed for DDKT readiness (interaction p=0.087).

Secondary Outcome: Transplant Knowledge

At baseline, mean transplant knowledge T-score was 52.1 (SD=9.7). Compared to the SOC arm, a larger increase in transplant knowledge was observed for the YPT group over time (Figure 3; interaction p < 0.001). The difference between YPT and SOC was 1.5 points (ES = 0.15, p = 0.082) at 4 months and 4.1 points (ES = 0.42, p < 0.001) at 8 months. Race did not interact with treatment, indicating the effect of study arm on transplant knowledge after baseline did not differ substantially by race/ethnicity group (interaction p=0.70).

Secondary Outcome: New Steps toward LDKT and DDKT

At baseline, patients had taken a median of 1.0 steps towards LDKT (IQR = 4.0) and 2.0 steps towards DDKT (SD=3.0). Overall, the most common steps already taken at baseline were calling the transplant center to pursue evaluation, talking to people they trust about whether to get a living donor transplant, and making a list of people who might be living donors.

By the end of the study, YPT patients had taken a median of 3.0 (IQR = 3.0) new steps towards LDKT, compared to a median of 2.0 (IQR = 3.0) new steps in the SOC arm (RR: 1.12, 95% CI: 1.01 - 1.24, p=0.034). In addition to total new steps taken, YPT patients were more likely to take almost every individual new step towards LDKT and DDKT in comparison with the SOC arm (Table 3). Specifically, more YPT patients shared their need for a living donor with a large community (43.6% vs. 27.1%, p=0.001), shared educational materials about living donation with others in their life (86.0% vs. 67.0%, p<0.001), asked another person to tell others of their need for a living donor (63.8% vs. 49.3%, p=0.009), and asked potential donors to be tested (70.7% vs. 53.7%).

There was also a significant difference between groups in number of new steps taken towards DDKT (RR = 1.13, 95% CI: 1.05 – 1.22, p=0.002) with a median of 5.0 (IQR = 3.0) new steps taken for the YPT arm and 4.0 (IQR = 3.0) for the SOC arm. More YPT patients shared educational materials about DDKT with people in their life (87.9% vs. 67.3%, p<0.001) and talked to people they trust about whether to get a DDKT (87.2% vs. 67.6%, p<0.001). No heterogeneity of intervention effect was observed for race (interaction p=0.67).

Final Outcome – Transplant Pursuit

After a minimum of 18 months follow-up, 323 patients total (40.2%) were either waitlisted for DDKT or received a LDKT (57.0% YPT vs 43.0% SOC), with those receiving the YPT intervention faring better (Figure 4, log-rank p = 0.003; HR: 1.39, 95% CI: 1.12 – 1.74). This benefit was unchanged after adjusting for race/ethnicity (HR: 1.44, 95% CI: 1.15 - 1.79; p = 0.002). No statistically significant interaction was observed between race/ethnicity and intervention group (p>0.2).

During the same follow-up period, 95 patients (11.8%) received an LDKT, with 53 (13.0%) in the YPT condition and 42 (10.6%) in the SOC condition (Figure 5, log-rank p = 0.42). There was no evidence that the YPT intervention had an effect on LDKT rates (HR: 1.23, 95% CI: 0.81 – 1.85; p=0.329). No interaction was observed between race/ethnicity and intervention groups in receipt of LDKT (interaction p=0.943).

Evaluation of YPT. Over 95% of participants found the coaches and print materials helpful and easy to understand. There was no difference between race/ethnicity groups in evaluation ratings.

DISCUSSION

For patients presenting for transplant evaluation, the road to successful kidney transplantation can be long and challenging. A recent study found that the average time to complete evaluation and get waitlisted was 226 days (31). This is the first examination of the effectiveness of an individually tailored education and coaching program, *Your Path to Transplant,* being delivered over 8 months during pursuit of evaluation. This study found that kidney patients who received YPT were more likely to increase their transplant knowledge, increase their readiness to pursue DDKT and LDKT, take more steps toward DDKT and LDKT, and be listed for transplant than patients who received only traditional SOC education. While YPT patients also were more likely to share their interest with people about LDKT and solicit living donors, there were no differences in actual LDKT rates by education condition after 18 months.

This is one of the longest and most comprehensive educational interventions ever to occur within a transplant center. While similar transplant educational studies vary in duration from one day to 18 months (17, 22, 24, 32-34), most commonly, they involve interventions

occurring on evaluation day or during a single clinical visit with supplemental information provided afterwards for additional self-study (35, 36). Multiple studies now support expanding the length of interventions, involving living donors, and including multiple resources within interventions like videos, print materials, and coaching (17, 24, 32).

As part of their conversations, YPT coaches spent considerable time attempting to overcome commonly reported SES barriers to transplant (17-19). For example, during the coaching sessions, they provided information about low-cost or free transportation to the transplant center, dental care, and child care services, and discussed practical topics like where to park at the center and which bus route would help patients most easily get to the transplant center. Similarly, Basu et al., found that 4% of patient navigator encounters addressed transportation challenges (37).

In examining other interventions shown to increase transplant-seeking behaviors in racial/ethnic minorities, patient-level interventions using patient navigators (37, 38), home-based education with a minority health educator (17, 39), culturally targeted websites (33, 40), and culturally congruent transplant programs (41) have been found to be effective. At the patient and family level, discussions between participants and social workers (36), web-based education (33, 42), home-based educational meetings with patients (43), and meetings using technology to seek donors (44), and involving a patient's social network, including potential living donors (45) have proven effectiveness. At the provider and system level, research has found that transplant facilities with specifically tailored toolkits to coordinate patient care (46, 47), and risk-based approaches identifying patients in need of targeted care (48, 49) were more successful. Interventions including multiple levels of the socioecological model may be needed, perhaps in combination (50-52).

Finally, this study has several limitations. First, the RCT was conducted in a single, high-volume transplant center in an urban area and, thus, may be limited in generalizability. Selection bias also potentially threatens generalizability of the study, as 21.6% (536 out of 2483) of pre-randomized patients declined to participate in the study, with a lower proportion of Hispanic patients providing consent. Over time, nearly 20% of patients could not complete all time points because they either died or became ineligible for transplant. Of the 80% that remained eligible for transplant over the entire 8- month time period, 36% were lost to follow-up by the 8-month visit, with a higher drop-out rate in the YPT group compared to SOC, potentially biasing our conclusions. If all patients still eligible for transplant but lost to follow-up were considered to be "not taking actions" towards LDKT, we find that patients in the YPT arm were still more likely to be taking actions than SOC (YPT: 130/325=40% vs SOC: 101/325=31%, p=0.017). Finally, it is possible that some of YPT's treatment effect was diluted by patients who did not read the tailored education reports or watch the videos on their own at home. Since telephonic coaching sessions reviewed the content from these materials, even patients using the materials on their own but less often would still have some exposure to the intervention.

YPT provides an innovative option for supporting a racially and ethnically diverse ESKD patient population facing the many challenges of transplant evaluation and finding a living donor. This study revealed that it is possible to improve transplant patients' knowledge, pursuit of transplant, and wait-listing rates if a focused, coordinated education effort honoring patients' readiness and motivation to pursue DDKT and LDKT, addressing their unique SES barriers, and supporting them in taking critical transplant actions over time can be implemented. These individually tailored strategies could be embedded within traditional education programs at transplant centers to meet patients' educational needs.

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Disclosure

Dr. Amy D. Waterman, PhD owns the intellectual property to the transplant education product *Explore Transplant* and has licensed it at no-cost to a nonprofit, Health Literacy Media (HLM), who retains all revenue as to their sales. She serves as an unpaid consultant to HLM to ensure the accuracy of educational content. All other authors declare that they have no competing interests.

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Table 1: DDKT and LDKT Stages of Readiness Measurement

DDKT Survey Question	**Stage of Readiness**
I am not considering getting a DDKT in the next six months	Precontemplation
I am considering getting a DDKT in the next six months	Contemplation
I am preparing to get a DDKT in the next 30 days	Preparation
I am undergoing evaluation to get a DDKT	Action
I am listed and waiting to get a DDKT	Maintenance

LDKT Survey Question	**Stage of Readiness**
I am not considering taking actions in the next six months to pursue LDKT	Precontemplation
I am considering taking actions in the next 30 days to pursue LDKT	Contemplation
I am preparing to take actions in the next 30 days to pursue LDKT	Preparation
I am taking actions to pursue LDKT	Action

Table 2. Baseline patient characteristics overall and by randomized group

	Overall (N=802)	YPT (N= 407)	SOC (N= 395)
Age, mean (SD)	53.0 (13.1)	52.7 (13.0)	53.2 (13.3)
Sex, n (%)			
Men	486 (60.6)	239 (58.7)	247 (62.5)
Women	316 (39.4)	168 (41.3)	148 (37.5)
Race/ethnicity, n (%)			
Non-Hispanic Black	200 (24.9)	108 (26.5)	92 (23.3)
Hispanic	313 (39.0)	155 (38.0)	158 (40.0)
Non-Hispanic White	279 (34.7)	138 (33.8)	141 (35.7)
Other	11 (1.4)	7 (1.7)	4 (1.0)
Comorbidities, n (%)			
Diabetes	350 (43.6)	157 (38.6)	193 (48.9)
Hypertension	661 (82.4)	337 (82.8)	324 (82.0)
Polycystic kidney disease	89 (11.1)	44 (10.8)	45 (11.4)
Insurance, n (%)			
Medicare	122 (15.3)	56 (13.9)	66 (16.8)
Medicaid	221 (27.7)	119 (29.5)	102 (26.0)
Private Insurance (i.e. HMO, PPO)	427 (53.6)	221 (54.7)	206 (52.4)
Don't know	7 (0.9)	2 (0.5)	5 (1.3)
Other insurance	20 (2.5)	6 (1.5)	14 (3.6)
On dialysis, n (%)	560 (69.8)	275 (67.6)	285 (72.2)
Education, n (%)			
8th grade or less	19 (2.4)	6 (1.5)	13 (3.3)
Some high school	56 (7.0)	23 (5.7)	33 (8.4)
High School Diploma or GED	197 (24.6)	101 (24.8)	96 (24.3)
Some college or vocational school	253 (31.6)	129 (31.7)	124 (31.4)
College or vocational school degree	182 (22.7)	100 (24.6)	82 (20.8)
Some professional or graduate school	21 (2.6)	10 (2.5)	11 (2.8)
Professional or graduate degree	74 (9.2)	38 (9.3)	36 (9.1)
Transplant Education, n (%)			
Read brochures about transplants	504 (62.8)	258 (63.4)	246 (62.3)
Watched videos	215 (26.8)	111 (27.3)	104 (26.3)
Browsed Internet websites	429 (53.5)	222 (54.5)	207 (52.4)
Talked to doctors and other medical staff	701 (87.4)	357 (87.7)	344 (87.1)

Table 3. New steps towards LDKT and DDKT over the 8-month study period by randomized group

	Total N*	YPT N (%)	SOC N (%)	p-value
Steps toward LDKT				
Share education materials about living donation with people in your life	342	135 (86.0%)	124 (67.0%)	<0.001
Generally, talk to people you trust about whether to get a living donor transplant	270	109 (86.5%)	108 (75.0%)	0.026
Make a list of people who might be a living donor for you	280	87 (70.7%)	93 (59.2%)	0.062
Ask another person to tell others about your need for a living donor transplant	353	97 (63.8%)	99 (49.3%)	0.009
Ask potential donors to be tested	358	111 (70.7%)	108 (53.7%)	0.002
Give potential living donors the transplant center phone number	417	134 (69.4%)	129 (57.6%)	0.017
Share my need for a living donor with a large community (e.g., Facebook, Twitter, etc.)?	397	78 (43.6%)	59 (27.1%)	0.001
Steps toward DDKT				
Read information/watch videos about getting on the deceased donor waiting list	419	179 (88.6%)	157 (72.4%)	<0.001
Share educational materials about deceased donation with people in your life	387	160 (87.9%)	138 (67.3%)	<0.001
Generally, talk to people you trust about whether to get a deceased donor transplant	348	150 (87.2%)	119 (67.6%)	<0.001
Call the transplant center to pursue evaluation	219	97 (93.3%)	101 (87.8%)	0.256
Complete and mail back the transplant center's new patient medical forms	451	208 (95.9%)	207 (88.5%)	0.007
Invite someone to come to evaluation with you	286	125 (94.7%)	135 (87.7%)	0.063
Come to the transplant center to complete medical tests	499	232 (93.5%)	206 (82.1%)	<0.001
Follow-up with transplant coordinator until transplant evaluation is complete	462	178 (79.1%)	162 (68.4%)	0.012

*Total sample size not already doing step at baseline.

Figure 1. Study design

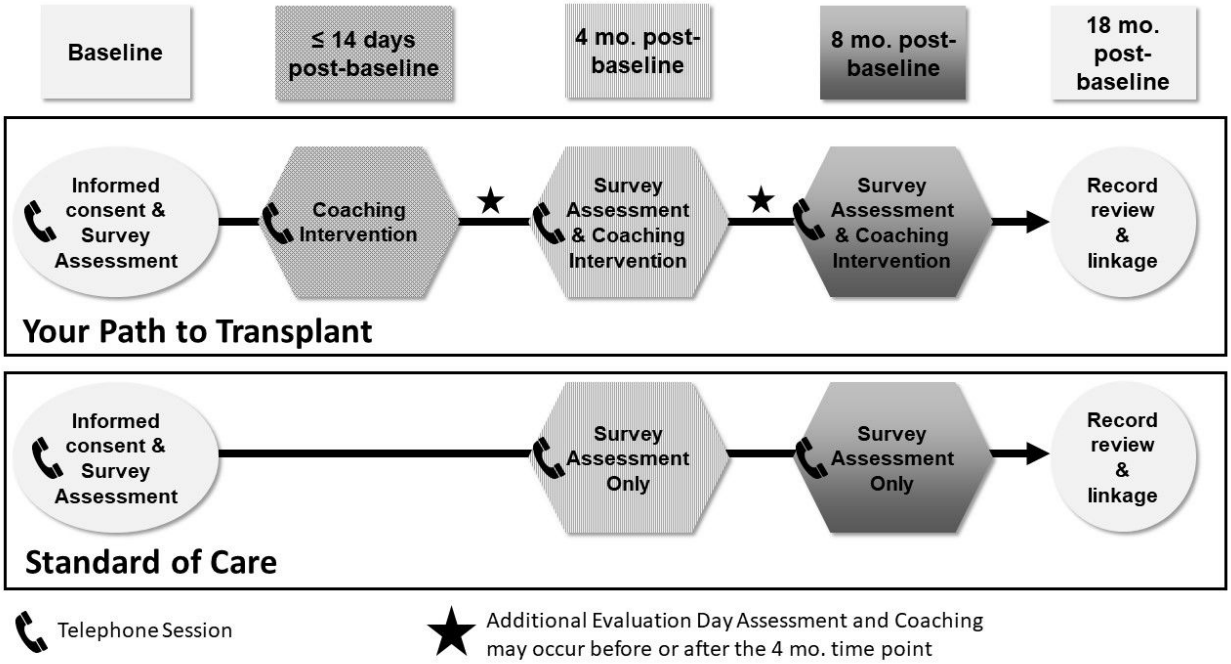


Figure 2. Your Path to Transplant Trial CONSORT Flowchart

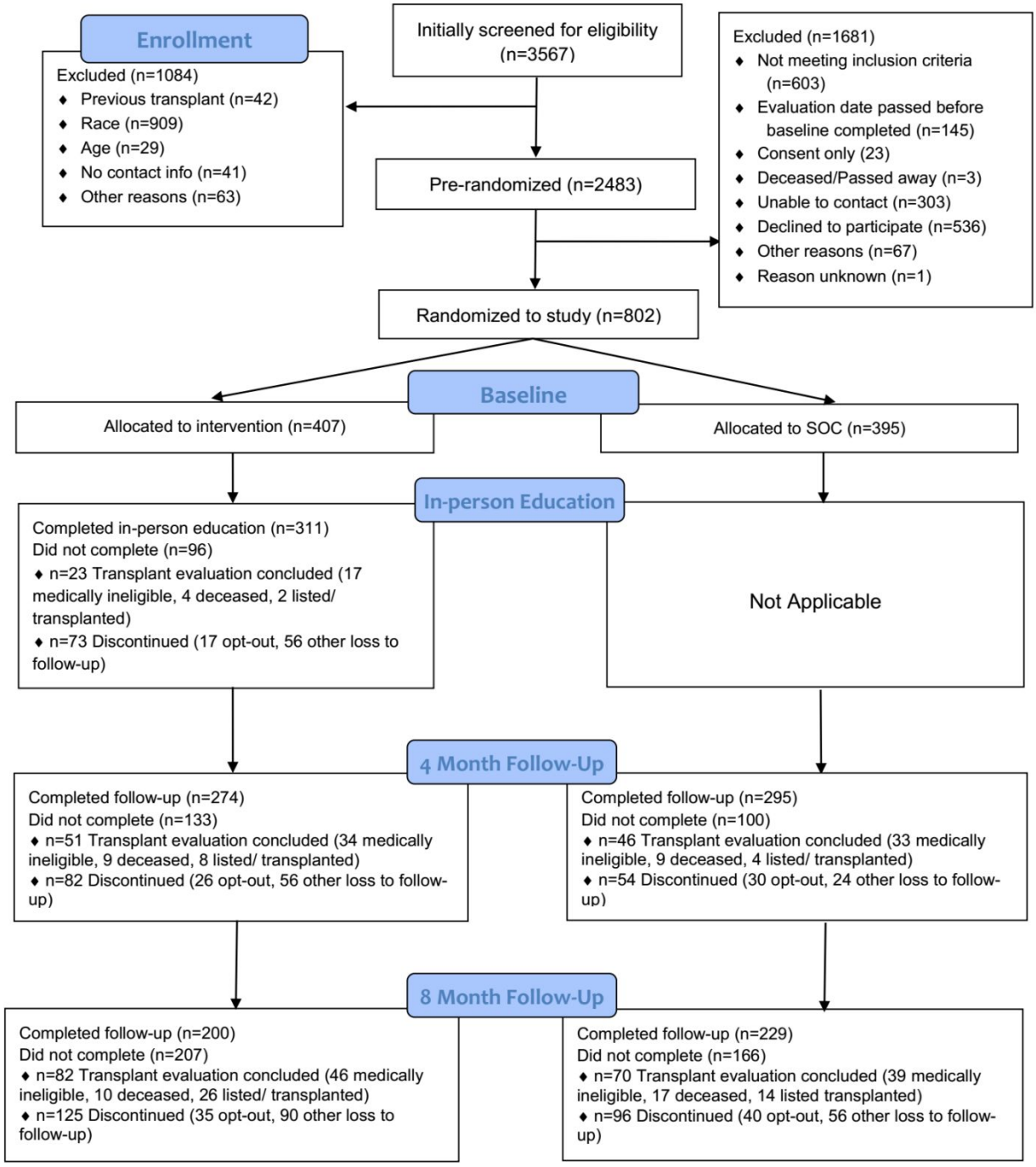
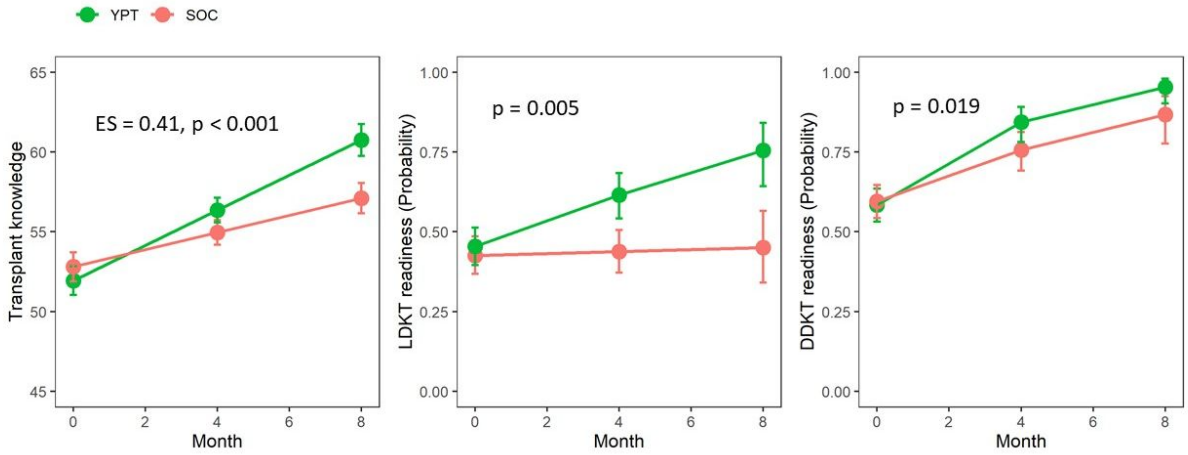


Figure 3. Transplant knowledge and readiness over time (mixed effect model predicted means and 95% confidence intervals)



Effect size and p-values are for comparison between YPT and SOC at month 8.

Figure 4: Waitlisting rate by randomized group

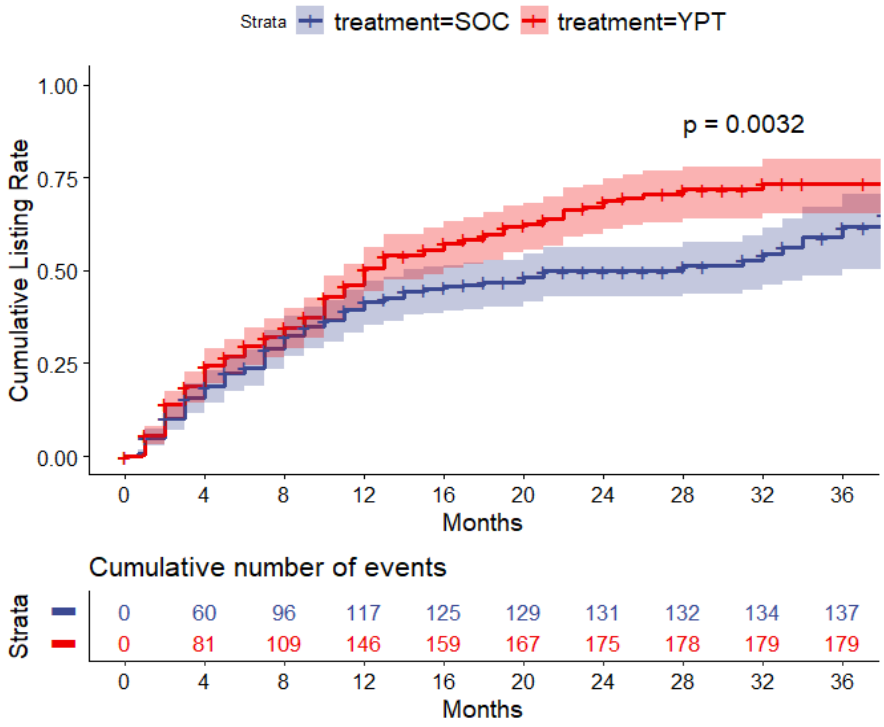


Figure 5: LDKT rate by randomized group

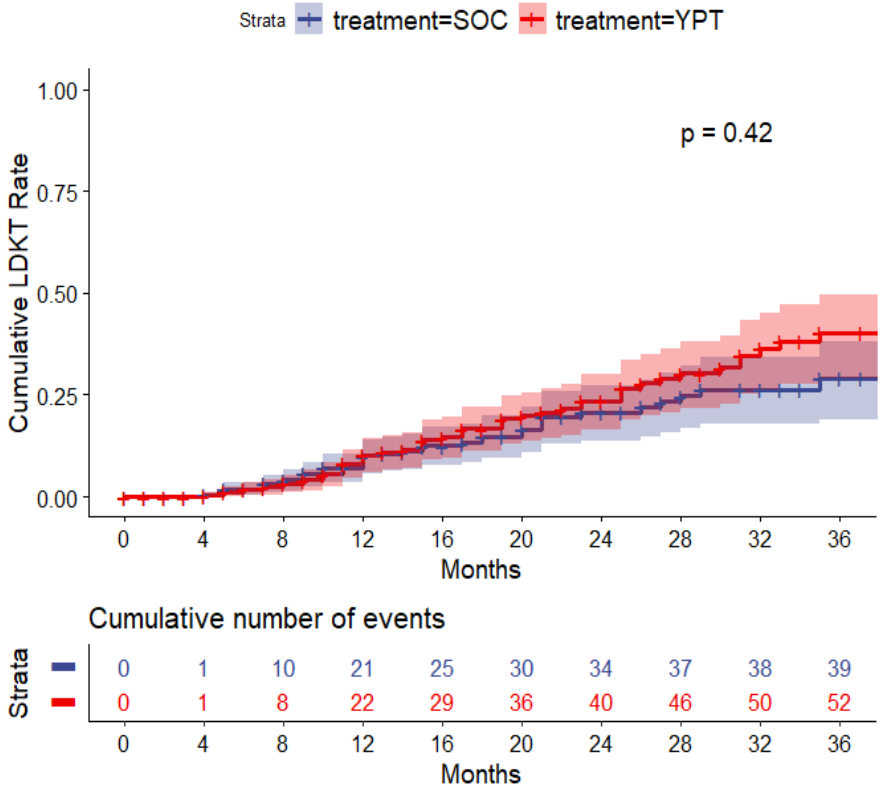


Table S1. Comparison between patients consented vs. declined to join the study (N = 2483)

	Consented	Declined
	N = 815	N = 1668
Age, years (mean (SD))	52.9 (13.1)	53.8 (13.3)
Male, n (%)	496 (60.9)	1075 (64.7)
Race/ethnicity, n (%)		
Hispanic (any race)	244 (29.9)	692 (43.5)
Non-Hispanic Black	208 (25.5)	246 (15.5)
Non-Hispanic White	349 (42.8)	507 (31.9)
Other	6 (0.7)	62 (3.9)
Unknown	8 (1.0)	83 (5.2)

Table S2: Patient Characteristics between dropouts and non-dropouts at 4 months (N=803)

	Drop out (n = 238)	Did not drop out (n = 565)	p value*
Age	54.68 (13.1)	52.24 (13.1)	0.016
Female	97 (41)	219 (39)	0.621
Race/ethnicity (%)			0.604
Black	60 (25)	140 (25)	
Hispanic	88 (37)	225 (41)	
White	89 (38)	190 (34)	
Comorbidities			
HBP (%)	187 (79)	474 (84)	0.156
Diabetes (%)	107 (45)	243 (43)	0.102
PKD (%)	16 (7)	73 (13)	0.004
Private Insurance (%)	114 (48)	314 (56)	0.063
Dialysis (%)	182 (77)	378 (67)	0.007
Education (%)			0.655
8th grade or less	6 (3)	13 (2)	
Some high school	16 (7)	40 (7)	
High school diploma or GED	64 (27)	133 (24)	
Some college or vocational school	80 (34)	173 (31)	
College or vocational school degree	46 (19)	136 (24)	
Some professional or graduate school	4 (2)	17 (3)	
Professional or graduate degree	21 (9)	53 (9)	
Employment (%)			0.115
Full-time	34 (15)	120 (21)	
Part-time	11 (5)	15 (3)	
Employment of others in household	8 (3)	42 (7)	
Retirement savings/pension	25 (11)	58 (10)	
Social security	57 (25)	110 (20)	
Unemployment	3 (1)	9 (2)	
Welfare/TANF	4 (2)	8 (1)	
Disability due to kidney disease	53 (23)	123 (22)	
Disability due to other causes	34 (15)	76 (14)	
Health (1-5)			0.665
Good, very good or excellent (3-5)	122 (51)	302 (53)	
Poor or fair (1-2)	115 (49)	263 (47)	
Treatment group, n (%)			0.01
YPT	138 (58)	270 (48)	
SOC	100 (42)	295 (52)	

*t-test for continuous variables and Fisher's exact test or Chi-square test for categorical variables

Table S3: Patient Characteristics between dropouts and non-dropouts at 8 months (N=802)

	Drop out (n = 376)	Did not drop out (n = 427)	p value*
Age	53.43 (13.8)	52.55 (12.5)	0.195
Female	150 (40)	166 (39)	0.801
Race/ethnicity (%)			0.889
Black	97 (26)	103 (25)	
Hispanic	145 (39)	168 (40)	
White	131 (35)	148 (35)	
Comorbidities			
HBP (%)	300 (80)	361 (85)	0.061
Diabetes (%)	168 (45)	182 (43)	0.409
PKD (%)	30 (8)	59 (14)	0.021
Private Insurance (%)	188 (50)	240 (56)	0.099
Dialysis (%)	280 (75)	280 (66)	0.006
Education (%)			0.337
8th grade or less	10 (3)	9 (2)	
Some high school	29 (8)	27 (6)	
High school diploma or GED	102 (27)	95 (22)	
Some college or vocational school	109 (29)	144 (34)	
College or vocational school degree	77 (21)	105 (25)	
Some professional or graduate school	9 (2)	12 (3)	
Professional or graduate degree	39 (10)	35 (8)	
Employment (%)			0.375
Full-time	59 (16)	95 (22)	
Part-time	15 (4)	11 (3)	
Employment of others in household	19 (5)	31 (7)	
Retirement savings/pension	41 (11)	42 (10)	
Social security	85 (23)	82 (19)	
Unemployment	6 (2)	6 (1)	
Welfare/TANF	6 (2)	6 (1)	
Disability due to kidney disease	83 (23)	93 (22)	
Disability due to other causes	51 (14)	59 (14)	
Health (1-5)			0.096
Good, very good or excellent (3-5)	186 (50)	238 (56)	
Poor or fair (1-2)	189 (50)	189 (44)	
Treatment group, n (%)			0.009
YPT	210 (56)	198 (46)	
SOC	166 (44)	229 (54)	

*t-test for continuous variables and Fisher's exact test or Chi-square test for categorical variables