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Effectiveness of Educational and Social Worker Interventions to Activate Patients' Discussion and Pursuit of Preemptive Living Donor Kidney Transplantation: A Randomized Controlled Trial

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Abstract

Background—Many patients with chronic kidney disease (CKD) have difficulties becoming actively engaged in the pursuit of pre-emptive living donor kidney transplantation.

Study Design—The Talking About Live Kidney Donation (TALK) study was a randomized controlled trial of the effectiveness of educational and social worker interventions designed to encourage early discussions and active pursuit of pre-emptive LKT among patients with progressive CKD.

Setting & Participants—We recruited participants with progressive CKD from academically affiliated nephrology practices in Baltimore, Maryland.

Intervention—Participants randomly received 1) "Usual Care" (routine care with their nephrologists), 2) "TALK Education" intervention (video and booklet), or the 3) "TALK Social Worker" intervention (video and booklet plus patient and family social worker visits).

Outcomes—We followed participants for 6 months to assess their self-reported achievement of behaviors reflecting their discussions about LKT and/or pursuit of LKT (discussions with family; discussions with physicians; initiating recipient evaluation; completing recipient evaluation; identifying a potential living donor).

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Measurements—We assessed outcomes via questionnaire at 1, 3, and 6-month follow up.

Results—Participants receiving Usual Care with their nephrologists (n=44), TALK Education (n=43), and the TALK Social Worker (n=43) were similar at baseline. TALK Study interventions improved participants' LKT discussion and pursuit behaviors, with the Social Worker leading to greater patient activation (participants' predicted probability (95% confidence interval) of achieving LKT discussions, evaluations, or donor identification over 6 months in Usual Care, TALK Education, and TALK Social Worker groups: 30% (20%–46%), 42% (33% –54%), and 58% (41% –83%), respectively (p=0.03).

Limitations—Our population was well educated and mostly insured, potentially limiting generalizability of our findings.

Conclusions—TALK interventions improved discussion and active pursuit of LKT among patients with progressive CKD and may improve their utilization of pre-emptive LKT.

Live kidney transplantation (LKT) is considered an optimal treatment strategy for many patients, particularly when initiated pre-emptively, or before patients require renal replacement therapy (RRT). [1,2] Despite this, LKT has been largely underutilized.[3,4] Reasons for underutilization of LKT are multifold and include patients' lack of knowledge about LKT,[5] hesitance to pursue LKT,[6,7] and difficulties identifying willing and eligible donors.[8–10]

Evidence suggests many patients with chronic kidney disease (CKD) have difficulties becoming actively engaged with the pursuit of LKT early enough in their disease progression to facilitate their utilization of LKT pre-emptively.[11,12] Patients often have difficulties discussing LKT with their families and health care providers[8,11–14], which presents a major roadblock to their pursuit and receipt of LKT. Early discussions help patients and families become informed about the risks and benefits of LKT, explore the feasibility of identifying potential donors, and take the steps necessary to complete donor and recipient medical evaluations in a timely manner. Patients and their families cite several self-reported difficulties discussing LKT, including not knowing how to initiate LKT discussions, feeling awkward about discussions, and their desires for professional help with navigating complex family issues related to LKT (e.g., needs of children or financial considerations).[6,13] Initiating and sustaining discussions may be particularly challenging to accomplish when patients who do not immediately require RRT experience denial regarding their impending need to consider or discuss LKT.[13,14]

Effective interventions that help patients and families engage in early discussions about LKT and encourage their active pursuit of LKT could improve patients' utilization of pre-emptive LKT. We studied the effectiveness of educational and social worker interventions to improve patients' discussions and pursuit of pre-emptive LKT in a randomized controlled trial.

Methods

Study Design

The Talking about Live Kidney Donation (TALK) Study was a 6-month, multi-site randomized controlled trial in which we randomly assigned with equal probability patients with advanced stage, progressive CKD to one of three parallel arms to receive: 1) usual care with their nephrologists ("Usual Care"); 2) a video and booklet encouraging patients to talk about LKT with their families and health care providers ("TALK Education"); and 3) the video and booklet plus social worker visits facilitating patients' and families' strategic discussions about ways to overcome self-identified barriers to pursuing LKT ("TALK Social

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Worker"). Participants could not feasibly be blinded to treatment group after receiving the educational and social worker interventions. Data collectors assessed outcomes using objective methods at 1, 3, and 6-months post randomization. The Johns Hopkins School of Medicine Institutional Review Board (IRB) approved all protocols and consent procedures. We initiated our trial registry application in November 2008, and we obtained IRB approval in December 2008. Trial registration was not completed until July 2009 due to an administrative delay.

Setting and Participants

We conducted the trial with patients recruited from academically affiliated and community-based nephrology practices in the Baltimore, MD metropolitan region. Participants were English-speaking patients with National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI) stages 3, 4, or 5 CKD who were deemed to have progressive CKD by their nephrologists and who had not yet initiated dialysis therapy. We revised our originally proposed protocol to include patients with stages 3 CKD prior to obtaining IRB approval and initiating the trial. We also revised our protocol to exclude patients who had previously received a transplant and to include patients who may have completed the transplant evaluation process but who had not yet received a transplant. The trial registration did not reflect these protocol changes.

To determine eligibility, we screened billing and medical records of patients seen at nephrology practices. We considered patients potentially eligible if they were age 18 to 70 and had no evidence of: cancer within 2 years prior to recruitment date, stage IV congestive heart failure, end-stage liver disease, severe peripheral vascular disease, pulmonary hypertension, unstable coronary artery disease, history of HIV, chronic (debilitating) infections, or prior kidney transplant. We discussed patients' appropriateness for considering LKT given patients' the severity of their decreased kidney function, their rate of kidney function decline, or other clinical conditions with their nephrologists. We attempted to recruit only patients deemed by their nephrologists to be potentially appropriate for eventual LKT.

Enrollment and Randomization

We enrolled study participants after they completed a screening telephone questionnaire (to confirm eligibility and informally assess their ability to speak English) and a home visit. At the home visit, study staff completed the baseline questionnaire and health literacy assessment. We employed blocked random allocation (blind and generated by a study coordinator not involved in participant recruitment) at each site to recruit participants with equal probability to each study arm. The randomization sequence was created using Stata 9.0 (StataCorp, www.stata.com) statistical software and was stratified by center with 1:1:1 allocation using 24 random blocks of 5 sizes, ranging from 3 to 15. Allocation was concealed from research staff enrolling participants until the home visit, at which time a study coordinator not involved in data collection or performing home visits revealed group assignments.

Interventions

The TALK educational video and booklet encouraged patients to consider LKT and to initiate discussions about LKT with their families and health care providers. The 20-minute video featured English-speaking ethnically diverse patients and their family members describing their experiences with discussing and pursuing LKT, and it featured health professionals describing factors for patients and families to discuss and consider with regard to LKT. The booklet was designed to be readable by English-speaking patients or their family members with low to moderate health literacy. It provided an overview of the process

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of LKT from recipient and donor perspectives, information on publicly available education about LKT, and it provided 'model conversations' which patients and families could use as examples for initiating and sustaining LKT discussions.

The TALK Social Worker intervention helped patients and their families elicit and overcome their self-identified barriers to discussing (with their families or health care providers) LKT or pursuing LKT. At the baseline enrollment home visit, study staff invited TALK Social Worker participants to participate in a 60-minute counseling session with a Master's degree trained licensed social worker. During meetings, the social worker helped patient participants self-identify barriers to considering or pursuing LKT. At the conclusion of initial meetings, the social worker asked participants if they were willing to meet a second time with a family member or friend in attendance. During second meetings, the social worker helped patients and family members identify, as a group, barriers to considering or pursuing LKT. Details regarding TALK Study interventions are described elsewhere.[15]

Study staff provided participants assigned to the TALK Education group with the educational video and booklet during the enrollment home visit. Study staff offered to review the video and booklet with participants if participants desired, and staff encouraged participants to share the video and booklet with their family members or friends. Study staff brought their own video equipment (i.e., DVD player) to assist participants who might not have had the capacity to watch a video in their homes and staff were trained to help participants listen to the video in the event they reported being physically unable to watch it (i.e., due to visual impairment). Participants assigned to the TALK Social Worker group received the TALK Education video and booklet in this fashion as well, but they were also invited to participate in social worker meetings, held at the study coordinating center at Johns Hopkins University, within one to three weeks after the enrollment home visit. Participants assigned to the Usual Care group received their usual clinical care with their nephrologists after the enrollment home visit. Participants in all groups may have received educational materials from their nephrologists as they would during routine clinical practice during the course of the study, but participants assigned to Usual Care did not receive any educational materials other information on kidney disease or LKT from study staff.

Primary and Secondary Outcome Assessments

Our primary outcome was participants' self-reported achievement of at least one of five key behaviors important in the process of discussing and pursuing LKT, including: 1) discussing LKT with at least one family member; 2) discussing LKT with their physicians; 3) initiating the clinical evaluation for potential LKT recipients; 4) completing the clinical evaluation for potential LKT recipients; and 5) identifying a potential live kidney donor. We assessed participants' completion of LKT discussion/pursuit behaviors via telephone interviews at baseline and at 1, 3 and 6 months after enrollment. We also assessed the effect of interventions on participants' interest in LKT and their concerns about risks associated with LKT (both rated on a 10-point scale ranging from 0 (not at all interested/concerned) to 10 (extremely interested/concerned)).

Baseline Assessments

We assessed participant characteristics that could influence their likelihood to accomplish LKT discussion/pursuit behaviors during follow up, including their sociodemographic characteristics, health literacy (assessed via the Rapid Estimate of Adult Literacy in Medicine (REALM), which categorizes persons as having "3rd grade and below", "4th to 6th grade," 7th to 8th grade" and "9th grade and above" literacy levels),[16] and clinical characteristics (estimated glomerular filtration rate at baseline (assessed via chart review), comorbidity (using an adapted version of the Charlson Index),[17] and depression presence

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assessed via the validated PHQ-9 (score 10 or greater indicating depression present).[18] We assessed participants' family structure as well as objective measures of participants' perceived family functioning (problem solving, communication, and general functioning subscales of the McMaster Family Assessment Device[19]; scored 1 (healthy functioning) to 4 (unhealthy functioning).

We also assessed factors which could influence participants' prior consideration of LKT, including their prior receipt and perceived adequacy of information about LKT, the length and intensity of their relationships with their nephrologists, and the occurrence and perceived adequacy of their prior discussions about dialysis or transplantation with their nephrologists. We also assessed participants' satisfaction with discussions, whether they discussed how differences between dialysis and transplantation could affect their quality of life, life expectancy, money matters, and family well-being, and whether their nephrologists had encouraged them to begin to take steps to seek a transplant.

Intervention Uptake and Fidelity Assessments

We asked participants randomized to the TALK Education and TALK Social Worker groups to report whether they watched the TALK video and read the booklet at 1, 3 and 6 months after randomization. We also asked participants to rate the usefulness of the video and booklet. We audio-recorded and transcribed all TALK Social Worker sessions. Two study staff members reviewed each transcript and independently assessed the social worker's successful execution of 7 behaviors defined in the study protocol (including explaining her role, assessing patients' understanding of kidney disease, assessing patients' readiness to pursue LKT, assessing patients' barriers to pursuing LKT, and helping patients identify steps to overcome their self-identified barriers to pursuing LKT). Staff members met to verify findings and adjudicated any differences with a third investigator.

Statistical analysis

We examined differences in participant characteristics at baseline among study groups. In our primary intent-to treat analysis, we quantified participants' probability of achieving the primary outcome (at least one new LKT discussion/pursuit behavior) over 6-months. The main independent variable was the randomly assigned intervention group. We hypothesized *a priori* that the TALK Social Worker intervention, which was more intensive than the TALK Educational intervention would be more effective at improving patients' LKT discussion/pursuit behaviors. To assess whether more intensive interventions led to participants' greater achievement of discussion/pursuit behaviors among study groups, we used longitudinal generalized estimating equations specifying a logit model for binary outcomes with an autoregressive correlation structure. The model incorporated assessments of behaviors achieved at baseline, 1, 3, and 6-month follow up assessments. A priori, we estimated that a sample size of 120 persons (40 per group) was needed to have 95% power (two sided α of $p<0.05$) to detect a trend in which there was a two-fold difference in LKT behaviors between the TALK Education and Usual Care groups and an additional 10% incremental benefit with the TALK Social Worker. Our principal analyses assumed data were missing at random and did not impute missing values. In a sensitivity analysis, we also performed multiple imputation to account for missing values. In post hoc analyses, we described the types of behaviors participants achieved over follow up. We also quantified changes in participants' perceived concerns about LKT among study groups, using generalized estimating equations accounting for participants' self-reported level of each concern at baseline, 1, 3, and 6-months. Analyses were performed using STATA MP Version 10.0 (StataCorp, www.stata.com).

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Results

Participant Screening, Enrollment, and Retention

Between February 2009 and August 2010, we assessed the eligibility of 5,450 people of whom 495 were eligible for participation. The most common reason for non-eligibility was patient age less than 18 or greater than 70 years. We stopped the trial in March 2011, after determining that all participants completed their follow up or could not be contacted at 6-months. Of the 495 patients who entered screening, we consented and enrolled 130. Overall, 91%, 85% and 80% of participants completed 1, 3, and 6-months follow up. (Figure 1)

Participants' Sociodemographic, Clinical, and Family Characteristics

Participants were sociodemographically diverse. The median estimated glomerular filtration rate at baseline among all participants was 26 (range, 12–51) mL/min/1.73 m^2. Participants had low comorbidity scores, and less than a quarter had depression at baseline. Over half of participants were married and approximately half had at least one living parent. The median number of children and siblings per participant were 2 (interquartile range [IQR], 2–3) and 2 (IQR, 1–4), respectively. (Table 1)

Participants' Prior Information about LKT, Relationship with Nephrologists, and Discussions about Dialysis or Transplant

Only one third (n=43, 33%) of all participants reported they had received prior information on LKT and over half (n=80, 62%) reported they were "not well" or "slightly well" informed about LKT at baseline. Participants reported being under nephrologists' care for a median of 2.5 (IQR, 1–5) years, and most saw nephrologists at least once every 2 to 3 months. A majority of participants reported they had previously discussed dialysis or transplantation with their nephrologists, and most were highly satisfied with these discussions. Fewer than 10% reported they had not previously discussed dialysis at all and more than a quarter reported they had not previously discussed transplantation at all. Fewer than half reported they had discussed with their nephrologists how differences between transplantation and dialysis might affect their future length of life, money matters, families' well-being, or need for help from family or friends. Most reported their nephrologists had not yet instructed them to take steps to pursue a kidney transplant. (Table 2)

Intervention Uptake and Fidelity

A majority of participants in the TALK Education (n=32, 74%) and TALK Social Worker (n=37, 86%) groups reported they watched the TALK video, and most participants in the TALK Education (n= 36, 84%) and TALK Social Worker (n=29, 67%) groups reported they reviewed the TALK booklet. Among those watching the video, most reported they shared the video with a family member (TALK Education: n=19, 59%; TALK Social Worker: n=22, 60%). Among those reading the booklet, most reported they shared the booklet with a family member (TALK Education: n=20, 56%; TALK Social Worker: n=24, 83%). Nearly all participants reported the video (TALK Education: n=32, 100%; TALK Social Worker: n=34, 94%) and the booklet (TALK Education: n=36, 100%; ; TALK Social Worker: n=29, 100%) were somewhat or very useful.

Most (n=29, 67%) participants assigned to the TALK Social Worker group attended both patient and family member social worker visits (for 10 to 60 minutes duration). The social worker adhered to the protocol in over 90% of visits.

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Post-Intervention Achievement of LKT Discussion/Pursuit Behaviors

Over half (n=71, 55%) of all participants had completed none of the LKT discussion/pursuit behaviors at baseline. Many participants had achieved multiple LKT behaviors, reflecting 1 of 12 patterns. The patterns of behaviors achieved varied at baseline and over follow up. (Table 3) Overall, 34 (26%), 46 (36%), and 61(47%) participants achieved at least one additional LKT discussion/pursuit behavior by 1, 3, and 6 months follow up, respectively. (Figure 2a) In a GEE model accounting for missing values and repeated measures, participants' predicted probability of achieving one additional LKT discussion/pursuit behavior over 6 months follow up in the Usual Care, TALK Education and Talk Social Worker groups was 30% (95% confidence interval [CI], 20%–46%), 42% (95% CI, 33%–54%) and 58% (5% CI, 41%–83%), respectively (p=0.03). (Figure 2b) Sensitivity analyses employing multiple imputation of missing values yielded similar findings (predicted probabilities of achieving one additional discussion/pursuit behavior over 6 months follow up in the Usual Care, TALK Education and Talk Social Worker groups was 32% [95% CI, 21%–48%], 43% [95% CI, 33%–56%], and 59% [95% CI, 41%–85%], respectively [p=0.05]). Among the 61 participants achieving new LKT discussion/pursuit behaviors over 6 months, participants most frequently achieved LKT discussions with their families (n=53, 87%) and LKT discussions with their physicians (n=44, 72%), followed by identifying a potential live kidney donor (n=38, 62%), starting the transplant recipient evaluation (n=15, 25%), and completing the transplant recipient evaluation (n=7, 11%). (Table 4)

Secondary Outcomes

Overall, participants' interest in LKT was high at baseline and remained high among all three study groups over follow up. Participants were most concerned about how LKT might affect donors' safety, money matters, feelings of guilt or coercion, and recipients' safety or feelings of guilt. Participants' concerns were similar among study groups and did not statistically significantly change over follow up. (Table 5)

Discussion

Patients' early engagement in discussions about LKT and their active pursuit of LKT before they initiate dialysis are essential to their pre-emptive utilization of LKT. TALK Education and TALK Social Worker interventions yielded higher rates of LKT discussions and pursuit among patients with CKD when compared to usual care. Patients' interest in LKT was high throughout the study, despite their concerns regarding LKT (including about the safety of LKT for donors and recipients). TALK Study interventions did not appear to resolve these concerns.

To our knowledge, this is the first randomized controlled trial to study the effectiveness of interventions to encourage patients' consideration of pre-emptive LKT during nephrology care. In a previous study of patients with end stage renal disease (ESRD), in-home family discussions about LKT led by transplantation professionals improved patients' access to LKT.[20] However, factors influencing consideration of LKT may differ for patients with ESRD and patients with CKD, because CKD patients are often asymptomatic, frequently lack awareness or deny their need for kidney transplantation, and the focus of CKD and ESRD care may be different.[21,22] Another randomized controlled trial demonstrated CKD education could prolong patients' time to dialysis initiation and improve mortality, but it did not examine the impact of this education on pre-emptive pursuit of LKT. [23,24]

Interventions employing accessible educational resources and non-physician medical professionals are increasingly promoted to activate patients toward desired health behaviors (e.g., treatment adherence). [25–31] TALK interventions were designed to help patients and

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families with a range of health literacy overcome frequently encountered difficulties with initiating and sustaining LKT discussions.[13] Although the TALK Social Worker intervention appeared to only modestly improve discussion/pursuit behaviors when compared to the TALK Educational intervention, social workers are trained to help patients address a broad range of logistical and psychological challenges associated with family decisions and may be particularly well suited to support patients' family discussions about LKT.[32,33] Master's level educated social workers already participating in the multidisciplinary clinical care of patients with ESRD across the U.S. may represent an ideal resource for feasibly providing similar interventions to pre-ESRD patients.

Our study has limitations. Many study participants had eGFRs greater than 20 mL/min/1.73 m^2, which may be earlier than when many nephrologists begin to consider initiating discussions about RRT with their patients. However, planning for pre-emptive LKT may require significant time given the need for patients to navigate a variety of complex potential barriers to LKT.[13] Three participants reported they had achieved all LKT pursuit behaviors at baseline, which could have limited our estimate of the effectiveness of TALK interventions. Patients who have achieved no LKT behaviors at baseline may be the most appropriate targets for TALK interventions. Second, our population was well-educated and mostly insured, potentially limiting generalizability of our findings to those (e.g., of low socioeconomic status) who may face the most profound barriers to pre-emptive LKT.[4] Third, we did not correlate LKT discussion and pursuit behaviors with patients' actual receipt of LKT. Studies further validating LKT pursuit behaviors as intermediate outcomes for LKT may enhance clinicians' confidence in TALK interventions. Fourth, barriers to LKT not addressed by TALK interventions (e.g., financial barriers[4]), could also greatly influence patients' receipt of LKT. Nonetheless, poor discussion about LKT has been repeatedly identified as an important barrier to LKT warranting intervention.[6,12,13,34] Finally, since TALK Study interventions did not provide extensive information about risks and benefits of LKT, supplemental interventions focusing on the risks and benefits of LKT could better inform patients about their concerns and possibly further activate patients' pursuit of pre-emptive LKT.

In conclusion, TALK educational and social worker interventions helped patients discuss and actively pursue pre-emptive LKT. Use of TALK interventions paired with the provision of detailed information about the risks and benefits of pre-emptive LKT could enhance patients' utilization of this therapy.

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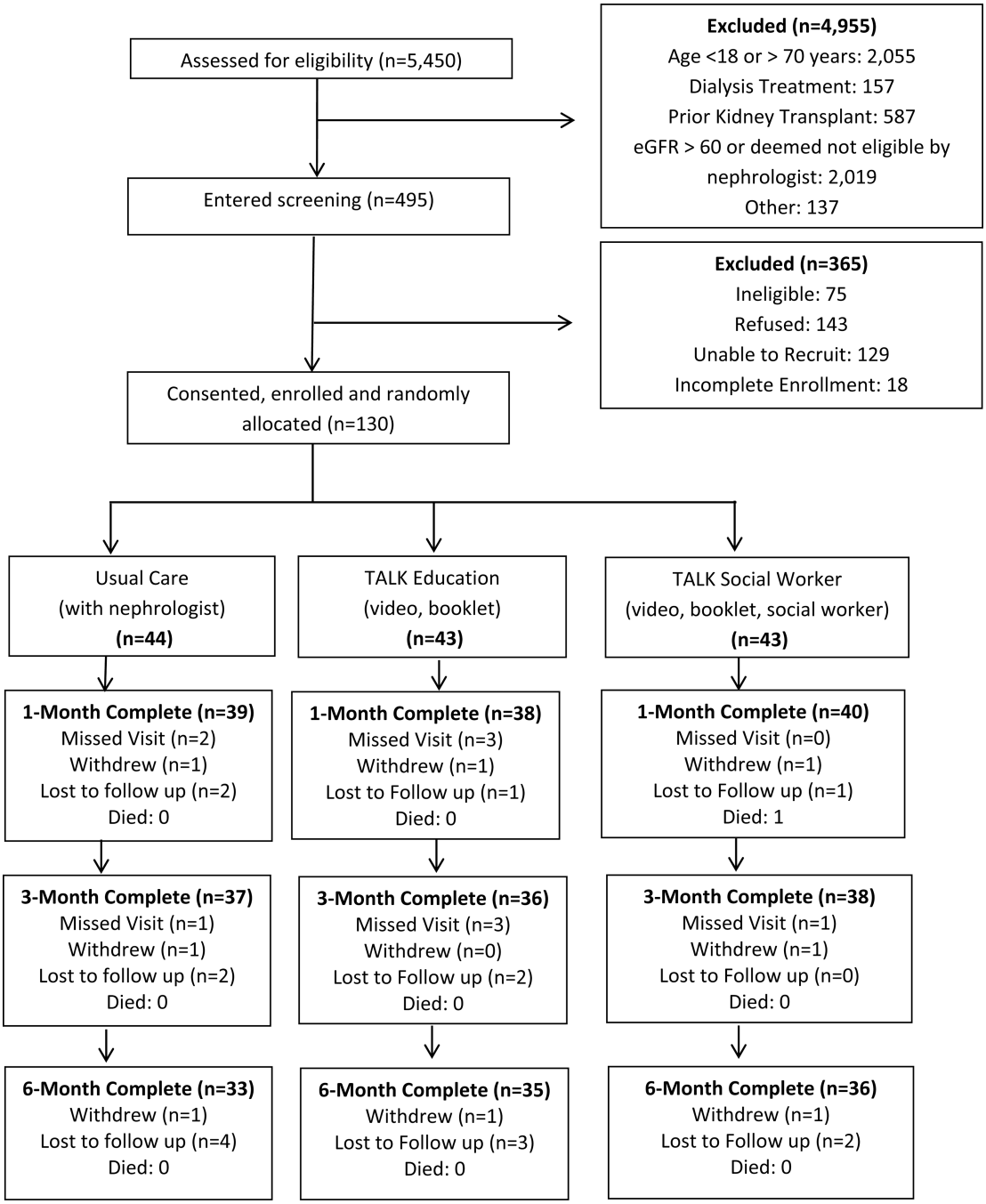

Figure 1.

Study flow diagram for eligibility, screening, consent, enrollment, randomization and follow-up. Estimated glomerular filtration rate (eGFR) expressed as mL/min/1.73 m^2. TALK, Talking About Live Kidney Donation study.

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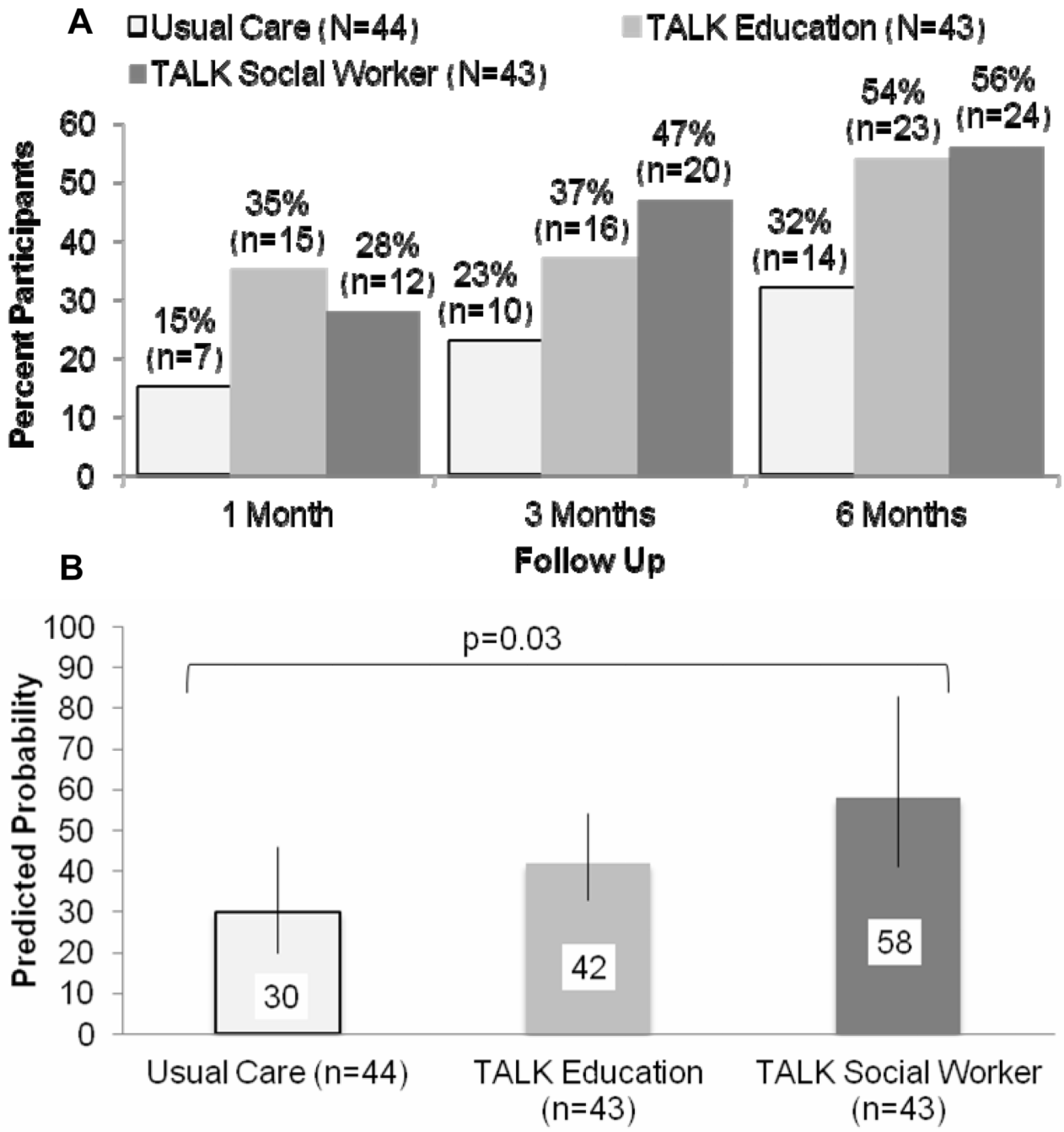

Figure 2.

(A) Participants in the Talking About Live Kidney Donation (TALK) who achieved at least one additional LKT discussion/pursuit behavior from baseline to 1, 3, or 6 months follow-up. (**B**) Predicted proportion of participants achieving one additional LKT discussion/pursuit behavior over 6 months. *Participants' predicted probability of achieving one additional discussion/pursuit behavior at either 1, 3 or 6 months follow up in generalized estimating equation model accounting for missing values and repeated measurements; Missing Data: 5 (Usual Care), 5 (TALK Education), 3 (TALK Social Worker) observations missing at 1 month; 7 (Usual Care), 7 (TALK Education), 5 (TALK Social Worker) observations missing

at 3 months; 11 (Usual Care), 8 (TALK Education), 8 (TALK Social Worker) observations missing at 6 months. TALK, Talking About Live Kidney Donation study.

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Table 1

Participants' sociodemographic, clinical, and family characteristics

		Usual Care (n=44)*	TALK Education (n=43)*	TALK Social Worker (n=43)*	p-value
Sociodemographic Characteristics					
Age (y)		60 [52–65]	60 [52–65]	59 [53–67]	0.7
Male sex		18 (41)	17 (40)	17 (40)	0.9
Race/ethnicity					0.7
	Non-Hispanic White	22 (50)	17 (40)	21 (49)	
	Non-Hispanic Black or African American	20 (46)	23 (53)	19 (44)	
	Non-Hispanic Other	1 (2)	3 (7)	3 (7)	
	Hispanic	1 (2)	0 (0)	0 (0)	
Education					0.6
	Less than 12th Grade	11 (25)	7 (16)	6 (14)	
	High school Graduate	11 (25)	16 (37)	13 (30)	
	Some College	22 (50)	20 (47)	24 (56)	
Health insurance*	Medicare	14 (32)	19 (44)	23 (53)	0.1
	Medicaid	9 (20)	10 (23)	9 (21)	0.9
	Private	28 (64)	22 (51)	24 (56)	0.5
	Other	4 (9)	3 (7)	4 (9)	0.9
	Uninsured	2 (5)	2 (5)	0(0)	0.5
Employment					0.5
	Employed Full or Part Time	23 (52)	18 (42)	17 (40)	
	Retired or Disabled	18 (41)	24 (56)	24 (56)	
	Unemployed	3 (7)	1 (2)	2 (4)	
Household income					0.5
	> $20,000	29 (66)	32 (74)	28 (65)	
	<= $20,000	9 (20)	9 (21)	14 (33)	
	Don't Know/Refused	6 (14)	2 (5)	1 (2)	

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		Usual Care (n=44)*	TALK Education (n=43)*	TALK Social Worker (n=43)*	p-value
Health literacy					0.6
	3rd grade and below	8 (18)	10 (23)	6 (14)	
	4th to 6th grade	4 (9)	2 (5)	2 (5)	
	7th to 8th grade	1 (2)	3 (7)	5 (11)	
	9th grade and above	31 (71)	28 (65)	30 (70)	
Clinical Characteristics					
eGFR ***		26 [12–51]	25 [12–35]	27 [17–51]	0.3
eGFR <20ml/min/1.73m^2		5 (11)	5 (12)	3 (7)	0.9
Comorbidity score **, ***		2 [0–7]	2 [0–9]	2 [0–10]	0.6
Comorbidity score tertile					0.7
	Lowest tertile, 0–1 points	11 (25)	11 (26)	12 (28)	
	Middle tertile, 2–3 points	19 (43)	16 (37)	13 (30)	
	Highest tertile, 4–10 points	12 (27)	16 (37)	17 (40)	
	Not calculated§	2 (5)	0 (0)	1 (2)	
Depression‡		9 (21)	7 (16)	8 (19)	0.9
Family Characteristics					
Married		28 (64)	26 (60)	25 (58)	0.9
At least one parent living		23 (52)	21 (49)	20 (47)	0.8
Number of children		2 [2–3]	2 [1–3]	2 [1–3]	0.5
Number of siblings		2 [1–4]	3 [1–4]	2 [1–3]	0.09
Family functioning	Problem Solving	2 [1–3.5]	2 [1–4]	2 [1–4]	0.5
	Communication	2 [1–3]	2 [1–3.4]	2 [1–3.5]	0.6
	General Functioning	1.9 [1–3]	1.9 [1–3.5]	2 [1–4]	0.6

Note: Unless otherwise indicated, values for continuous variables given as median [IQR]; values for categorical variables, as number (percentage). eGFR, estimated glomerular filtration rate; TALK, Talking About Live Kidney Donation study.

*Health insurance categories not mutually exclusive; each category compared across all study groups independently

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[**] Comorbidity score ranging from 0 (least comorbidity) to 21 (most comorbidity)

[***] Values in brackets reflect the range.

[§] Score not calculated in 3 study participants who reported they were unsure as to the presence of some comorbidities assessed in the comorbidity score

[‡] Depression diagnosis assessed as present with PHQ-9 score >=10

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Table 2

Participants' prior information about Living Kidney Donor Transplantation, relationship with nephrologist, and prior discussions about dialysis or transplantation at baseline

	Usual Care (n=44)	TALK Education (n=43)	TALK Social Worker (n=43)	p-value
Prior Information about Living Kidney Donor Tx				
Received prior information (Yes)	15 (34)	14 (33)	14 (33)	0.9
Perceived adequacy of information				0.5
Not well informed	13 (30)	17 (40)	19 (44)	
Slightly well informed	12 (27)	7 (16)	12 (28)	
Moderately well informed	15 (34)	12 (28)	8 (19)	
Very well or extremely well informed	3 (7)	7 (16)	4 (9)	
Not reported	1 (2)	0 (0)	0 (0)	
Length and intensity of relationship with nephrologist				
Years seeing current nephrologist	2.5 [1–6]	2.5 [2–5]	2.5 [1–5]	0.3
Frequency of nephrology visits				0.6
At least once a month	6 (14)	8 (19)	4 (9)	
At least every 2 to 3 months	26 (59)	20 (47)	25 (58)	
At least every 6 months to once a year	10 (23)	13 (30)	12 (28)	
Whenever patient has a problem	0 (0)	2 (5)	1 (2)	
Not reported	2 (0)	0 (0)	1 (2)	
Prior discussions about dialysis or Tx				
Participant and nephrologist ever previously talked about dialysis or Tx (Yes)	27 (61)	29 (67)	26 (60)	0.8
Satisfaction with discussions about dialysis or Tx*				0.4
Not at all satisfied	1(4)	1(3)	3 (12)	
A little satisfied	7 (26)	3 (10)	2 (8)	
Mostly satisfied	7 (26)	11 (38)	11 (42)	
Completely satisfied	12 (44)	13 (45)	9 (35)	
Not reported	0 (0)	1 (3)	1 (3)	

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	Usual Care (n=44)	TALK Education (n=43)	TALK Social Worker (n=43)	p-value
Extent kidney doctor has discussed dialysis *				0.9
Not at all	2 (7)	2 (7)	2 (8)	
A little	7 (26)	10 (34)	7 (27)	
Mostly	8 (30)	9 (31)	5 (19)	
Completely	9 (33)	8 (28)	12 (46)	
Not reported	1 (4)	0 (0)	0 (0)	
Extent kidney doctor has discussed Tx *				0.7
Not at all	6 (22)	9 (31)	7 (27)	
A little	7 (26)	10 (34)	7 (27)	
Mostly	5 (19)	4 (14)	8 (31)	
Completely	8 (30)	6 (21)	4 (15)	
Not reported	1 (4)	0 (0)	0 (0)	
Participant and nephrologist previously discussed how dialysis or Tx could affect participants'…. *				
Quality of life	14 (52)	14 (48)	13 (50)	0.7
Length of life	7 (26)	12 (41)	9 (35)	0.5
Money matters	4 (15)	4 (14)	3 (12)	0.9
Families' well-being	9 (33)	8 (28)	6 (23)	0.7
Need for help from family or friends	8 (30)	9 (31)	7 (27)	0.9
Participant instructed by nephrologist to take steps ** toward Tx	7 (16)	11 (26)	11 (26)	0.2

Note: Data are presented as number (percentage) or median [IQR].Tx, transplantation.

* These questions assessed only among participants stating they had previously discussed dialysis and Tx. Percentages reflect the percent of participants with these responses among those with prior discussions.

** (e.g. medical testing, discussions with family)

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Table 3

Number and pattern of LKT pursuit behaviors achieved by participants at baseline and 6 months follow up

No. of Achieved Behaviors	Pattern of Behaviors					Baseline (P=0.6)			6 Months (P = 0.3)		
	Discussed with physician	Discussed with Family	Started Recipient Evaluation	Completed Recipient Evaluation	Identified Potential Donor	Usual Care (n=44)	TALK Education (n=43)	TALK Social Worker (n=43)	Usual Care (n=44)	TALK Education (n=43)	TALK Social Worker (n=43)
0						25 (57)	24 (56)	22 (51)	15 (34)	11 (26)	8 (19)
1		•				3 (7)	0 (0)	2 (5)	0 (0)	4 (9)	6 (14)
1	•					2 (5)	3 (7)	2 (5)	3 (7)	3 (7)	2 (5)
2	•		•			0 (0)	1 (2)	1 (2)	1 (2)	0 (0)	1 (2)
2		•			•	7 (16)	6 (14)	6 (14)	7 (16)	5 (12)	4 (9)
2	•	•				0 (0)	0 (0)	0 (0)	1 (2)	4 (9)	1 (2)
3	•	•	•			0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
3	•	•			•	4 (9)	4 (9)	7 (16)	10 (23)	7 (16)	16 (37)
3		•	•	•		0 (0)	0 (0)	0 (0)	0 (0)	1 (2)	0 (0)
4	•	•	•	•		1 (2)	5 (12)	1 (2)	5 (11)	3 (7)	2 (5)
4	•	•	•	•		0 (0)	0 (0)	1 (2)	0 (0)	0 (0)	0 (0)
5	•	•	•	•	•	2 (5)	0 (0)	1 (2)	2 (5)	5 (12)	3 (7)

Note: Data are presented as number (percentage).
TALK, Talking About Live Kidney Donation study.

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Table 4

Types of new Living Donor Kidney Transplantation behaviors achieved by participants by 6 months follow-up

New Living Donor Kidney Tx Behavior	Usual Care (n=44)	TALK Education (n=43)	TALK Social Worker (n=43)	p-value
Discussed with family	11 (25)	20 (47)	22 (51)	0.1
Discussed with physician	13 (30)	16 (37)	15 (35)	0.05
Identified potential donor	10 (23)	12 (28)	16 (37)	0.09
Started recipient evaluation	5 (11)	6 (13)	4 (9)	0.1
Completed recipient evaluation	0 (0)	5 (12)	2 (5)	0.04

Note: Values shown are number (%). Some participants achieved more than 1 new behavior at each assessment: 14, 23, and 24 total participants achieved at least 1 living donor kidney transplantation behavior by 6 months (see Fig 2).
TALK, Talking About Live Kidney Donation Study; Tx, transplantation.

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Table 5

Participants' ratings on their interest in and concerns about living donor kidney transplantation

	Usual Care		TALK Education		TALK Social Worker		
Variables	**Baseline**	**6 mo**	**Baseline**	**6 months**	**Baseline**	**6 months**	**p-value**
Interest in living donor kidney Tx	10 (7–10)	9 (7–10)	8 (5–10)	8 (6–10)	9 (5–10)	8 (5–10)	0.4
Level of concern about how it would affect…							
Recipients' need for family help with recovery	5 (0–8)	3 (0–7)	4 (0–8)	5 (0–9)	6 (0–8)	5 (0–10)	0.2
Recipients' money matters	5 (2–10)	5 (2–10)	8 (5–10)	7 (3–10)	6 (4–10)	5 (4–9)	0.8
Donors' money matters	7 (4–10)	8 (4–10)	8 (5–10)	8 (5–10)	8 (4–10)	8 (5–9)	0.9
Recipients' safety during surgery	7 (3–10)	5 (3–10)	7 (5–10)	7 (5–10)	8 (4–10)	8 (4–10)	0.7
Donors' safety during surgery	9 (7–10)	9 (6–10)	9 (8–10)	9 (6–10)	10 (6–10)	10 (6–10)	0.6
Donors feeling guilty or pressured	7 (5–10)	5 (0–8)	8 (3–10)	8 (2–10)	8 (2–10)	7 (1–8)	0.5
Recipients feeling guilty or indebted to donor	7 (4–10)	6 (4–8)	8 (4–10)	6 (4–10)	8 (2–10)	7 (4–10)	0.4
Recipients' relationships with donors	5 (0–8)	3 (0–6)	3 (0–9)	2 (0–6)	5 (0–9)	5 (1–8)	0.4

Note: Rating are presented as median (IQR). Ratings measured on a scale of 0 (not interested/concerned) to 10 (extremely interested/concerned). TALK, Talking About Live Kidney Donation Study; Tx, transplantation.