ORIGINAL ARTICLE

Ethnic background is associated with no live kidney donor identified at the time of first transplant assessment—an opportunity missed? A single-center retrospective cohort study

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SUMMARY

Patients from ethnocultural minorities have reduced access to live donor kidney transplant (LDKT). To explore early pretransplant ethnocultural disparities in LDKT readiness, and the impact of the interactions with the transplant program, we assessed if patients had a potential live donor (LD) identified at first pretransplant assessment, and if patients with no LD initially received LDKT subsequently. Single-center, retrospective cohort of adults referred for kidney transplant (KT) assessment. Multivariable logistic regression assessed the association between ethnicity and having a potential LD. Cox proportional hazard analysis assessed the association between no potential LD initially and subsequent LDKT. Of 1617 participants, 66% of Caucasians indicated having a potential LD, compared with 55% of South Asians, 44% of African Canadians, and 41% of East Asians ($P < 0.001$). In multivariable logistic regression analysis, the odds of having a potential LD identified was significantly lower for African, East and South Asian Canadians. No potential LD at initial KT assessment was associated with lower likelihood of LDKT subsequently (hazard ratio [HR], 0.14; [0.10–0.19]). Compared to Caucasians, African, East and South Asian and African Canadians are less likely to have a potential LD identified at first KT assessment, which predicts a lower likelihood of subsequent LDKT.

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Key words
African Canadian, Asian Canadian, equitable access, ethnocultural disparity, kidney transplant, live donor kidney transplant, transplant education

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Introduction

Compared to staying on dialysis, kidney transplant (KT) is associated with better survival [1–5] and quality of life [6,7]. LDKT is preferred to deceased donor KT (DDKT), owing to better outcomes [8–11] and scarcity of deceased donors. However, LDKT is often underutilized [10,12]. Studies have demonstrated ethnic disparities in access to KT in the US [13–21], Europe [22–24], and Canada [25–27]. The large majority of the studies, however, primarily assessed African Americans, Hispanics, and Native Americans [28–30], and rarely patients

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with Asian heritage. We recently reported that African, East and South Asian Canadians had less chance to receive LDKT compared to Caucasians [31].

Applying the trans-theoretical model of behavior change to transplant decision-making helps to understand the stages of readiness from initially considering to actively pursuing LDKT [32,33]. This process usually begins with realizing and accepting the need to identify potential living donors, and taking initiatives to engage in discussions with them [32,34–36]. There are multiple religious, cultural, and social factors that may influence the decision to explore LDKT and finding a potential LD [14,37,38].

Patients in several jurisdictions in Canada (including our center) and in Europe, will undergo at least some transplant workup at the referring dialysis or predialysis clinic. Subsequently the patients are seen in pretransplant assessment at the transplant center. At this assessment, patients are routinely asked if they have a potential LD identified. A positive response to this question does not necessarily mean that a LD is ready to proceed with evaluation, but demonstrates that the patient has contemplated LDKT, has considered potential donor candidates, and has perhaps engaged in discussions with them. In other words, a positive answer to this question likely reflects an advanced stage of LDKT readiness [32,33,37]. A negative response, on the other hand, may imply that the patient is not aware of LDKT, had some degree of hesitancy exploring this option, or that they tried but failed to identify a potential LD. In other words, a negative answer indicates the presence of some types of barriers, some of which may be related to culture, religion, social, or emotional factors [39,40].

Receiving culturally competent education improves readiness to pursue LDKT [41,42]. Patients participate in education sessions and receive education material at the transplant center during the pretransplant assessment, but it has been well recognized that LDKT education should also be occurring in the dialysis and predialysis clinics. Furthermore, the education and support should be repeated, even after wait-listing, to reduce potential disparities in access to LDKT [43]. The potential impact of the education currently provided to patients at the transplant center and the existence or impact of ongoing support in dialysis units to explore LDKT while on the waiting list is unknown.

Very little is known about the readiness to explore LDKT among ethnic groups other than African Americans, or outside the US[35,44–46]. To our knowledge, no studies have evaluated the association between having a potential living donor identified at the first pretransplant assessment (an indicator of LDKT readiness) and ethnicity. Moreover, no reports evaluated whether having a potential living donor identified at the first pretransplant assessment predicts subsequent receipt of LDKT. The answer to this question would inform us about the impact of the education received at the pretransplant assessment or thereafter. Accordingly, using a retrospective Canadian cohort dataset, we assessed if non-Caucasian ethnicity is associated with lower odds of having a potential LD identified at the time of first pretransplant assessment. We also evaluated if having a potential living donor identified at first pretransplant assessment predicts the receipt of LDKT.

Patients and methods

Study design and sample

Single-center, retrospective cohort of adults (≥18 years) referred to the Toronto General Hospital for KT assessment between January 1, 2006 and December 31, 2013. We excluded multi-organ transplant candidates and patients who did not have information regarding potential LD or had missing psychosocial information. Ethics approval was obtained from the University Health Network Research Ethics Board (REB # 15-8863 AE). The clinical and research activities being reported are consistent with the Principles of the Declaration of Istanbul as outlined in the "Declaration of Istanbul on Organ Trafficking and Transplant Tourism".

Data sources and management

Information about having a potential LD identified at the time of pretransplant assessment is documented in the clinical notes in the Organ Transplant Tracking Record (OTTR) software, our electronic medical record system since the year 2000 for patients referred, wait-listed, transplanted, or undergoing follow-up care at our center. These notes were searched and information about potential LD (yes or no) was recorded on a data collection form designed for this study. We also recorded the relationship of the potential donor to the recipient. This information was then entered into our research database.

The remaining of our data collection procedures have been described [31,47]. Briefly, we abstracted and recorded information about ethnicity, language barrier, employment status, and marital status from the pretransplant social work assessment notes [31,47].

The data collected for this study were audited and merged with our in-center research database, the Comprehensive Renal Transplant Research Information System (CoReTRIS) [48]. CoReTRIS contains recipient, donor, transplant, laboratory, pathology, treatment, and follow-up data for all patients who received a KT at our center since the year 2000. These data have been abstracted from patient charts (electronic and paper), audited for completeness and quality, and entered into the database.

Exposure and outcome in the cross-sectional analysis

The main exposure of interest in the cross-sectional analysis was ethnicity as identified in our previous work [31,47]. The following categories were generated: (i) Caucasian, (ii) African Canadian, (iii) East Asian (e.g., Chinese, Japanese, Korean), (iv) South Asian (e.g., Indian, Pakistani, Sri Lankan, Indo-Caribbean), and (v) Other (Canadian First Nations, Pacific Islander, Middle Eastern, etc.,) [49,50].

In these analyses, the primary outcome was whether patients had a potential LD identified at the time of pretransplant assessment. In addition, we analyzed the number of potential donors and their relationship to the recipient. This relationship was categorized as: (i) spouse/partner, (ii) sibling, (iii) parent, (iv) child, (v) relative (biologically related but not sibling, i.e., grandparent, cousin, aunt etc.), (vi) unrelated (e.g., friend, colleague, etc.,), and (vii) unknown.

Exposure and outcome in the longitudinal analysis

The exposure of interest in the longitudinal analysis was whether a patient had a potential LD identified at the time of pre-transplant assessment (yes or no). The primary endpoint in this set of analyses was receipt of LDKT. Secondary outcome was receipt of DDKT and any KT (either LDKT or DDKT).

Patient follow-up and censoring events

The dates of referral to the transplant center, transplant (LDKT or DDKT), or death were stored in CoReTRIS [48]. The time of origin for the time to event analyses was the date of referral. Patients were followed until transplantation or study end (March 31, 2016). For the primary outcome (receipt of LDKT), censoring events included: declined for transplant (being deemed ineligible for transplantation), receipt of DDKT, death, lost to follow-up or, transfer to another center.

Covariates

Selection of demographic and clinical covariates for multivariable analyses was guided by theoretical considerations, clinical experience and data from the literature. Based on their potential association with our exposure and outcome variables we included recipient age, sex, marital status, ability to communicate in English, employment status, socioeconomic status, comorbidities at the time of referral, and history of previous transplant.

We considered the following comorbidities: diabetes mellitus, coronary artery disease, myocardial infarction, chronic heart failure, stroke (or transient ischemic attack), peripheral vascular disease, chronic lung disease, and nonskin cancers.In order to characterize demographic characteristics and socioeconomic status of participants accurately we used both individual level (marital status, employment) and more general, area-level measures such as the material deprivation index of the 2006 Ontario Marginalization Index (OMI) [51]. This is a census and geographically based index that allocates participants to a deprivation quintile, with quintiles 1–5 representing the least to the most deprived, respectively.

Statistical analysis

Categorical variables were described using frequencies and percentages while continuous variables were presented using mean (standard deviation, SD) for normally distributed data and median (interquartile range, IQR) for skewed variables. We evaluated the distribution of baseline characteristics across ethnic categories using parametric and nonparametric tests as appropriate.

We explored the association between ethnicity and having a potential LD identified using multivariable logistic regression models. We graphically assessed the cumulative probabilities of receiving a LDKT, KT, and DDKT using the Kaplan–Meier product limit method and examined differences across survival functions using the log-rank test.

We explored univariable and multivariable associations between exposures and outcomes using logistic regression models or Cox proportional hazard models. All patients included in the cross-sectional cohort ($n = 1617$) were also included in the time-to-event analyses. For all time-to-event analyses, date of referral was the time of origin. Patients who were deemed ineligible for transplantation, died, were lost to follow-up or

transferred to another center were censored at the time of the event. Patients who were still in the cohort at study end ($n = 355$) were censored at that time. For analyses using LDKT and DDKT, respectively, as endpoint, patients receiving DDKT and LDKT, respectively, were censored at the time of the transplant.

In a sensitivity analysis, we explored the associations between having a LD identified at the first pretransplant assessment and receiving an LDKT (primary endpoint), DDKT, or any KT (secondary endpoints) using competing risks regression models (competing event: death) (by Fine and Gray) [52].

The multivariable models were sequentially fitted with expanding sets of covariates. The proportional hazards assumption was tested using scaled Schoenfeld residuals. No important departures from proportionality were detected. Multicollinearity was assessed using a variance–covariance matrix (VCE > 0.4) and variance inflation factor (VIF > 5).

Missingness was less than 5% for all variables. We used the method of multiple imputation by chained equations to address missingness [53]. This method replaces missing values with a set of imputed values in different imputed datasets based on the joint distribution of existing values of variables entered in the imputation model. We performed analyses on five complete imputed datasets and combined the results using Rubin's rules.

All statistical analyses were performed using Stata 13.0 (StataCorp, College Station, TX, USA). A two-sided P value < 0.05 was considered statistically significant.

Results

After applying our selection criteria, 1,617 patients were included (Fig. 1). Baseline characteristics are presented in Table 1 and Table S1. Of the sample, 51% were Caucasian, 12% African Canadian, 12% East Asian, and 12% South Asian ($n = 827$, $n = 198$, $n = 197$, $n = 195$, respectively). A language barrier was primarily present among East Asians and South Asians ((25%, $n = 50$; 19%, $n = 36$, respectively). A greater proportion of African Canadians (36%) were in the most deprived socioeconomic category when compared to other ethnic groups.

Pre-emptive referral for transplant assessment was more frequent in Caucasians (21%, $n = 144$) compared to other ethnicities. African Canadians were more likely to have spent more than 24 months on dialysis (27%, $n = 51$) compared to other ethnicities (Table 1). Blood type B was most common in East and South Asians. African Canadians had fewer married, domestic, or common law partnerships, and a lower employment rate compared to other ethnic groups (Table 1).

Fifty-seven percent of the sample ($n = 923$) indicated having a potential LD identified at the first pretransplant assessment. This proportion was 66% among Caucasians, compared to 44% in African Canadians, 41% in East Asians, and 55% in South Asians, respectively (Table 2). The most common relationship to the potential donor was spouse and sibling. East Asians were the least likely, while Caucasians were the most likely to have unrelated/unknown donors. Only 22% of those who had a potential LD identified had more than one potential donors (Table 2). African Canadians were the least likely to have two or more potential donors identified.

Compared to Caucasians, African Canadians, East Asians, and South Asians were less likely to have a potential LD identified at the first pretransplant assessment (unadjusted odds ratio |OR|, 0.44; 95% confidence interval [CI] [0.32–0.60]; OR, 0.37; [0.27–0.52]; OR, 0.67; [0.48–0.92], respectively) (Table 3). Unadjusted OR estimates did not substantially change after adjustments for covariates. In the fully adjusted model (Model 4) African Canadians, East Asians, and South Asians were less likely to have a potential LD identified at the first pretransplant assessment compared to Caucasians (OR, 0.49; [0.35–0.70]; OR, 0.34; [0.23–0.48]; OR, 0.67; [0.47–0.96]). We also formally tested if there was a significant interaction between ethnicity and certain sociodemographic characteristics. When interaction terms were added to the logistic regression models, the interaction terms for the OMI ($P = 0.196$), age ($P = 0.374$) and sex ($P = 0.529$) were nonsignificant and did not qualitatively change any of the associations observed.

A total of 872 (54%) patients received a KT, 465 of those received LDKT while 407 received DDKT, within 8 years of referral (median follow-up was 2.59 [IQR 1.30–4.29] years). The median time from referral to the transplant program to receiving a transplant for patients with versus without a potential LD at presentation and also for the various ethnic groups is presented in Table S2. Patients who indicated not having a potential LD at the first pretransplant assessment had a much lower cumulative probability of receiving a LDKT (Fig. 2) or receiving a KT (Fig. 3) compared to those who had at least one. The cumulative probability of receiving a DDKT was higher among those who did not have a potential LD identified (Figure S1). In the fully adjusted model (Model 5), patients who did not have a

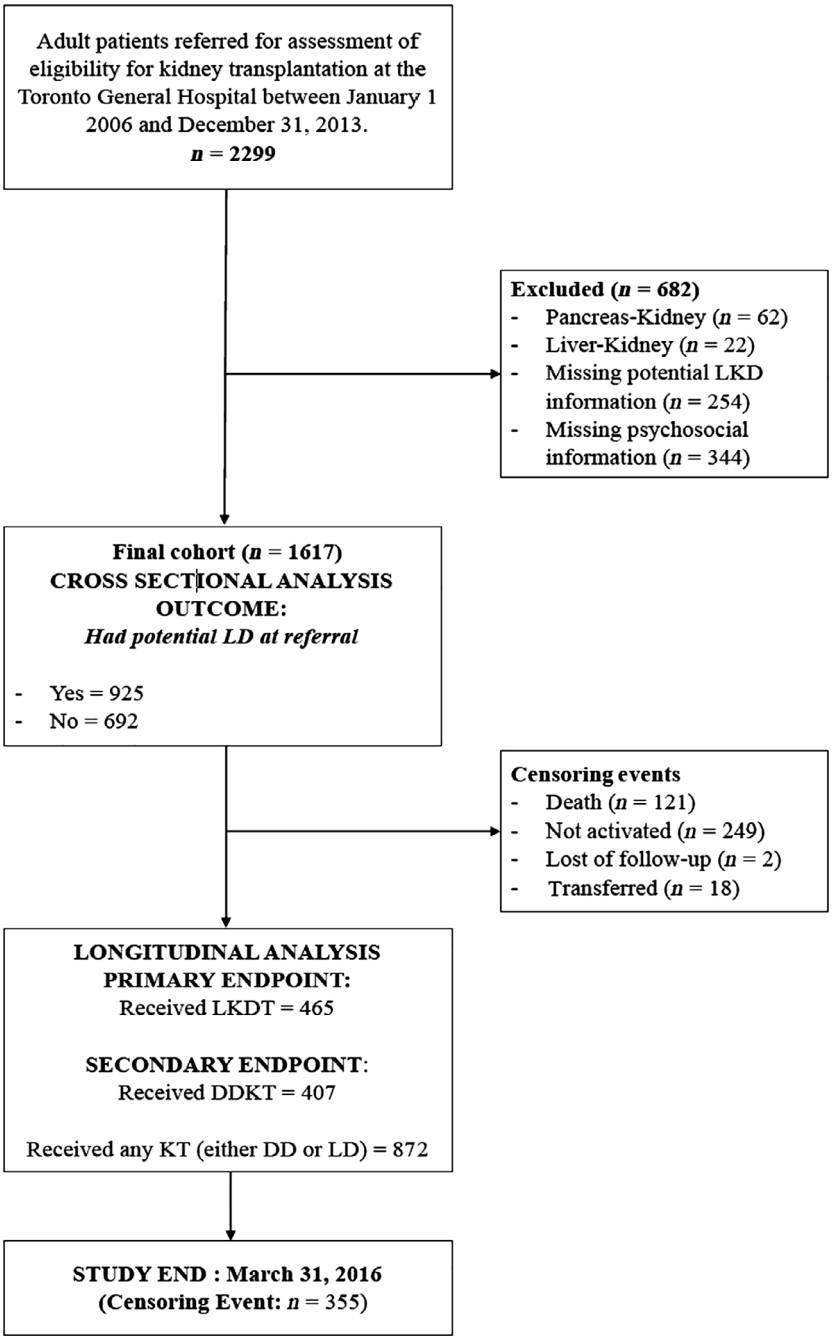

Figure 1 Study flow diagram.

potential LD at the first pretransplant assessment, were significantly less likely to receive a LDKT or any KT within 8 years of referral, compared to patients who had at least one potential LD (hazard ratio [HR], 0.14; [0.10–0.19]; HR, 0.57; [0.49–0.66], respectively) (Table 4). Importantly, the cumulative probability of receiving a LDKT has only minimally changed during the follow-up period for patients who did not have a potential LD at the first pretransplant assessment (Fig. 2). In a set of sensitivity analyses using the competing risk of death the associations between our exposure variable and the receipt of an LDKT, DDKT, or any KT were essentially the same as in our primary set of analyses (Table S4).

Among the patients who had potential LD identified at the first pretransplant assessment, 56% of the Caucasians, 31% of the African, 38% of the East Asian and 36% of the South Asian patients received a LDKT during the follow-up ($P < 0.01$) (Table S3).

Table 1. Baseline characteristics by ethnicity

Characteristics	Whole cohort (n = 1617)	Caucasian (n = 827, 51%)	African Canadian (n = 198, 12%)	East Asian (n = 197, 12%)	South Asian (n = 195, 12%)	P value
Living donor at referral (yes) n (%)	890 (57)	542 (66)	88 (44)	81 (41)	108 (55)	$P < 0.001$
Age, mean (SD)	51 (14)	51 (14)	50 (14)	50 (12)	50 (14)	$P = 0.53$
Male n (%)	986 (61)	509 (62)	114 (58)	113 (57)	137 (70)	$P = 0.058$
Time in dialysis n (%)						
Preemptive	229 (14)	144 (21)	13 (7)	23 (12)	28 (15)	$P < 0.001$
0–24 months	954 (59)	440 (63)	128 (67)	123 (65)	123 (67)	
>24 months	279 (17)	117 (17)	51 (27)	44 (23)	33 (18)	
Cause of ESKD n (%)						
GN	506 (31)	244 (30)	57 (29)	90 (46)	62 (32)	$P < 0.001$
DM	486 (30)	213 (26)	77 (39)	39 (20)	77 (39)	
PKD	160 (10)	121 (15)	7 (4)	11 (6)	7 (4)	
HTN	163 (10)	74 (9)	28 (14)	27 (14)	17 (9)	
Other/Unknown	302 (19)	175 (21)	29 (15)	30 (15)	32 (16)	
Had Previous Kidney transplant (yes) n (%)	131 (8)	82 (10)	6 (3)	19 (10)	13 (7)	$P = 0.020$
Blood Group n (%)						
A	535 (33)	325 (39)	56 (28)	44 (22)	49 (25)	$P < 0.001$
AB	85 (5)	42 (5)	7 (4)	20 (10)	10 (5)	
B	266 (16)	78 (9)	39 (20)	57 (29)	58 (30)	
O	731 (45)	382 (46)	96 (48)	76 (39)	78 (40)	
Marital Status n (%)						
Single, never married	328 (20)	168 (20)	45 (23)	36 (18)	35 (18)	$P < 0.001$
Married, domestic partnership or common law	1012 (63)	539 (65)	99 (50)	127 (64)	135 (69)	
Widowed, divorced or separated	272 (17)	117 (14)	53 (27)	34 (17)	25 (13)	
Unable to communicate in English n (%)	138 (9)	27 (3)	11 (6)	50 (25)	36 (19)	$P < 0.001$
Employment						
Unemployed	160 (10)	68 (8)	25 (13)	29 (15)	21 (11)	$P < 0.001$
Employed	532 (33)	309 (37)	44 (22)	71 (36)	58 (30)	
Other	908 (56)	444 (54)	128 (65)	95 (48)	111 (57)	
Ontario Marginalization Index n (%)						
1 (least deprived)	297 (18)	183 (22)	13 (7)	38 (19)	38 (19)	$P < 0.001$
2	338 (21)	196 (24)	28 (14)	47 (24)	41 (21)	
3	343 (21)	178 (22)	38 (19)	31 (16)	53 (27)	
4	279 (17)	137 (17)	38 (19)	30 (15)	30 (15)	
5 (most deprived)	303 (19)	113 (14)	71 (36)	44 (22)	28 (14)	
Comorbidity n (%)						
DM	609 (39)	282 (35)	92 (48)	54 (29)	84 (45)	$P < 0.001$
CAD/MI	396 (28)	192 (26)	47 (25)	29 (16)	66 (37)	$P < 0.001$
CHF	112 (7)	54 (7)	20 (10)	4 (2)	12 (6)	$P = 0.001$
Stroke/TIA	112 (7)	59 (7)	17 (9)	10 (5)	11 (6)	$P = 0.594$
PVD	157 (10)	85 (11)	25 (13)	12 (6)	11 (6)	$P = 0.051$
Chronic lung disease	108 (7)	68 (8)	6 (3)	8 (4)	10 (5)	$P = 0.032$
Nonskin cancer	124 (8)	79 (10)	18 (9)	8 (4)	5 (3)	$P = 0.004$

CAD, coronary artery disease; CHF, congestive heart failure; DM, diabetes mellitus; ESKD, end-stage kidney disease; GN, glomerulonephritis; HTN, hypertension; MI, myocardial infarction; PKD, polycystic kidney disease; PRA, panel reactive antibody; PVD, peripheral vascular disease; SD, standard deviation; TIA, transient ischemic attack.

Table 2. Type of potential living donor identified by ethnic group

Characteristics	Total with LD (n = 925)	Caucasians with LD (n = 542, 59%)	African Canadians with LD (n = 88, 10%)	East Asians with LD (n = 81, 9%)	South Asians with LD (n = 108, 12%)	P value
Relationship to potential donor n (%)						
Spouse/partner	299 (32)	184 (34)	20 (23)	26 (32)	42 (39)	P = 0.068
Sibling	294 (32)	167 (31)	29 (33)	34 (42)	29 (27)	P = 0.219
Parent	126 (14)	77 (14)	8 (9)	10 (12)	15 (14)	P = 0.764
Child	191 (21)	110 (21)	21 (24)	14 (17)	20 (19)	P = 0.660
Relative	121 (13)	70 (13)	10 (12)	9 (11)	16 (15)	P = 0.331
Unrelated/unknown	156 (17)	102 (19)	12 (14)	6 (7)	13 (12)	P = 0.039
Number of potential living donors n (%)						
1	722 (78)	419 (77)	77 (88)	65 (80)	85 (79)	P = 0.049
2 or more	203 (22)	123 (23)	11 (13)	16 (20)	23 (21)	

LD, living donor.

Table 3. Multivariable associations between ethnicity and having "a potential living donor identified" at the time of first post-transplant assessment (logistic regression)

Logistic regression model	African Canadian odds ratio (95% CI)	East Asian odds ratio (95% CI)	South Asian odds ratio (95% CI)
Model 1	0.44 (0.32, 0.60)	0.37 (0.27, 0.52)	0.67 (0.48, 0.92)
Model 2	0.42 (0.30, 0.58)	0.34 (0.24, 0.49)	0.64 (0.46, 0.91)
Model 3	0.49 (0.35, 0.69)	0.34 (0.24, 0.49)	0.65 (0.46, 0.93)
Model 4	0.49 (0.35, 0.70)	0.34 (0.23, 0.48)	0.67 (0.47, 0.96)

Model 1 Univariable; Model 2 Model 1 + age, sex, marital status, English communication; Model 3 Model 2 + OMI, employment status; Model 4 Model 3 + history of: diabetes, coronary artery disease/myocardial infarction, previous transplant. CI, confidence interval; OMI, Ontario Marginalization Index.

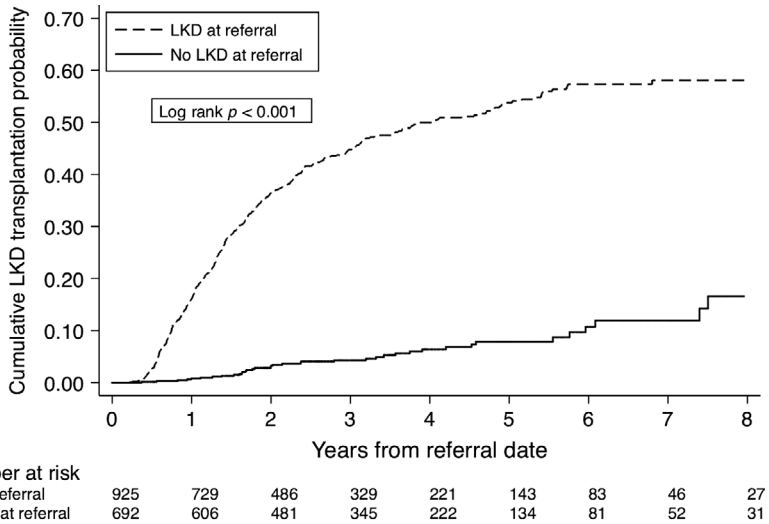

Figure 2 Cumulative probability of receiving a living donor kidney transplant in those with no potential living donor identified versus having a potential living donor identified at the time of first pretransplant assessment.

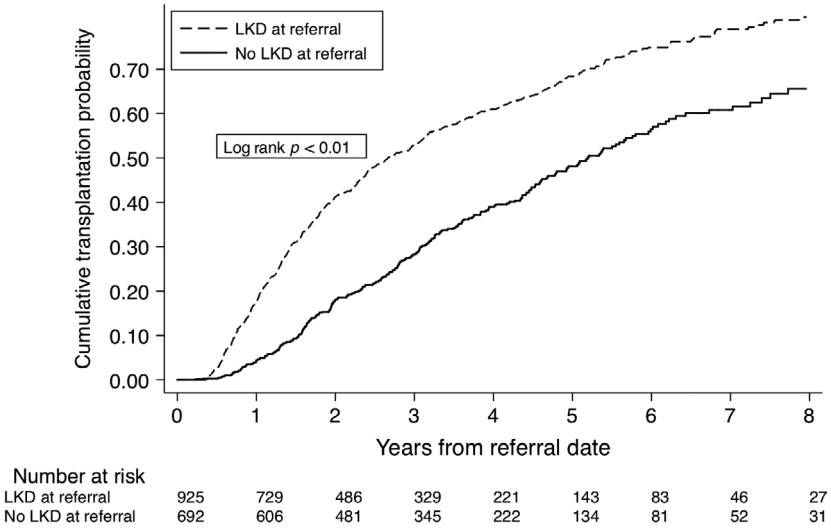

Figure 3 Cumulative probability of receiving any (living or deceased donor) kidney transplant in those with no potential living donor identified versus having a potential living donor identified at the time of first pretransplant assessment.

Table 4. Multivariable model of receiving LDKT or any KT for patients who did not have "a potential living donor identified" at the time of first pre-transplant assessment (Cox Proportional Hazards Model)

Cox proportional hazards model	Model 1 hazard ratio (95% CI)	Model 2 hazard ratio (95% CI)	Model 3 hazard ratio (95% CI)	Model 4 hazard ratio (95% CI)	Model 5 hazard ratio (95% CI)
LDKT	0.10 (0.07, 0.14)	0.12 (0.08, 0.16)	0.12 (0.09, 0.17)	0.12 (0.09, 0.17)	0.14 (0.10, 0.19)
Any KT	0.50 (0.43, 0.58)	0.52 (0.45, 0.61)	0.54 (0.47, 0.63)	0.55 (0.48, 0.64)	0.57 (0.49, 0.66)
DDKT	1.47 (1.21, 1.80)	1.37 (1.12, 1.69)	1.39 (1.13, 1.71)	1.44 (1.17, 1.77)	1.39 (1.13, 1.72)

Model 1: Univariable; Model 2: Model 1 + age, sex, marital status; Model 3: Model 2 + OMI, employment status; Model 4: Model 3 + history of: diabetes, coronary artery disease/myocardial infarction, blood group, previous transplant; Model 5: Model 4 + ethnicity, English communication; CI, confidence interval; DDKT, deceased donor kidney transplant; KT, kidney transplant; LDKT, living donor kidney transplant.

Discussion

In this retrospective study African, East and South Asian Canadian patients were significantly less likely to have a potential LD identified at the first pretransplant assessment compared to Caucasians, which potentially reflects lower LDKT readiness or the presence of barriers to the pursuit of LDKT. Furthermore, among patients who had a potential LD at their initial assessment, patients from minority groups were less likely to eventually have a LDKT compared to Caucasians. Finally, those who did not have a potential LD identified at first pretransplant assessment were less likely to eventually receive KT, particularly LDKT, over an 8-year follow-up period.

These findings suggest that ethnic background is a significant barrier to consider and pursue LDKT in Canada. This is important, since not receiving a LDKT may result in poorer health outcomes. Second, this also indicates that ethnic disparities in access to LDKT are present relatively early during the transplant process and may not change during the years after the initial transplant assessment. These observed inequities may be, at least in part, because of potentially modifiable cultural barriers. Better understanding of these barriers may allow the development of culturally competent LDKT education programs that may translate into increased LDKT rates in ethnic minorities, as previously shown [34,37,41,42,54–59].

Important differences between the transplant evaluation process at our center and the US need to be considered. At our center, referral for KT assessment is only accepted when most of the workup had been completed in the dialysis unit or predialysis clinic. In contrast, in the US, transplant workup is usually organized by the transplant programs after referral is received. As a result, many Canadian patients may present for their first pretransplant assessment with higher transplant

knowledge compared to patients in the US. This may result in a higher LD readiness and a higher number of potential LD identified at initial transplant assessment in our study.

After adjusting for several covariables, East Asians were the least likely to have a potential LD identified compared with other ethnic groups. Lower transplant knowledge and health literacy, concerns about the health of the donor, traditional health beliefs, and mistrust in the healthcare system may be responsible for these inequities [60–63]. Fear of death or disability after donating, and the wish to maintain an intact body may limit communication with healthcare workers and within families about donation in East Asian populations [62,64].

South Asians had the highest likelihood of having a potential LD identified among ethnic minorities; nonetheless, significantly lower than Caucasians. Although we did not have information about religious affiliation in this dataset, it is likely that a substantial proportion of South Asians were Muslim Canadians. In the United Kingdom, South Asian Muslims are more likely than South Asian non-Muslims (Hindus and Sikhs) to have negative attitudes toward organ donation [65] or toward accepting transplants [66]. Religious and traditional beliefs, lack of awareness in the community, and fear of transplant surgery have all been suggested as potential factors leading to this disparity [45,67,68]. In the United Kingdom, public campaigns have been implemented to increase awareness of organ transplantation in South Asian communities [69]. Moreover, centers which employ South Asian transplant coordinators have seen improved living donation rates among South Asians [70].

Socioeconomic deprivation, lower transplant knowledge, and health literacy may explain the lower likelihood of having a potential LD identified among African Canadians [14–16,29,44,46,71]. African Americans in the US were less likely to receive adequate transplant education and had lower transplant knowledge then Caucasians [14]. Moreover, African Americans perceived fewer benefits from LDKT and were less likely to accept if a LD volunteered [14]. Others have noted fear of transplantation and concerns about failing the required medical tests as barriers among African Americans [44,72,73].

In addition, socioeconomic, cultural, lifestyle, and genetic factors may lead to the higher risk of specific health concerns (diabetes, obesity, hypertension, CKD) in minority groups. This, in turn, may have an impact on both identifying potential donors and the medical suitability of potential donors [74–76].

Insufficient education from healthcare providers may contribute to the lower likelihood of having a potential LD identified. African Americans and Hispanics in the US receive less communication regarding transplantation and frequently +do not know how to proceed with the transplant process [14,77]. A US study reported that only 41% of the healthcare providers looking after patients on dialysis felt they had sufficient knowledge to answer patient questions regarding LDKT [13]. Similarly in Ontario, the majority of clinical staff in regional renal programs reported not feeling empowered to discuss LDKT- or KT-related questions [78,79]. Preliminary data from our ongoing mixed methods study suggest that East and South Asian and African Canadians were less willing to share information about their condition or education materials with potential donor candidates, and were less likely to have received an offer for LDKT compared to Caucasians. Furthermore, patients from these communities had lower transplant knowledge compared to Caucasians [35,44–46,63,71]. This is important, since there are numerous myths and misconceptions about LDKT and it is possible that these may be more prominent in some communities versus others. Without appropriate, culturally, and linguistically competent educational support, patients with language or cultural barriers may be unable to improve their transplant knowledge and pursue LDKT successfully.

In our longitudinal analysis, we found a strong association between not having a potential LD identified at the first pretransplant assessment and the subsequent likelihood of receiving a LDKT (hazard ratio [HR], 0.14; [0.10–0.19]). Very few patients who did not have a potential LD at the first pretransplant assessment received an LDKT during the follow-up. The cumulative incidence of LDKT remained stagnant among these patients for several years after receiving KT- and LDKT-specific education at the transplant center. This may indicate that there is no further exposure to transplant education after the initial assessment, or the education provided is unable to help patients overcome existing barriers.

Importantly, we found that patients from minority groups, who had a potential LD at the initial pretransplant assessment were less likely than Caucasian patients to eventually have a LDKT. Although we did not have information about the ethnicity of the potential donors, these data may suggest, that potential donors from ethnic minority groups are less likely to complete the donor workup process compared to Caucasians. Similar findings were reported for African Americans and the potential reasons include both social, cultural, and

medical factors [75,80–82]. Further research is needed to understand and potentially reduce those barriers.

The trans-theoretical model of behavior change can assist in designing and delivering effective LDKT education [32,37,41]. Culturally and linguistically competent education is important to support patients with language or cultural barriers to improve their transplant knowledge and pursue LDKT successfully. Studies in the United Kingdom have demonstrated that this may be achieved through informal community networks [83,84]. In the Netherlands, targeted, culturally competent, home-based educational programs were effective at improving transplant knowledge and resulted in increased access to LDKT amongst ethnic minorities [85–87]. Similar home-based education programs and using culturally competent transplant education in dialysis units improved transplant knowledge and readiness to pursue LDKT for African Americans in the US [41,42]. In the US, targeted programs for Hispanics [88] and African Americans [54] have been successful in increasing LDKT patient knowledge. Innovative approaches such as "Live Donor Champion" [89], that provides support for the patient to communicate with donor candidates, and the "Transplant Ambassador Program" [90] that involves experiential peer support from LDKT recipients and donors, are novel and potentially effective approaches to improve LDKT education. In Ontario, Canada, a new quality initiative in renal programs aims to encourage and support patients to explore KT and LDKT. This initiative includes a multifaceted education strategy and utilizes the Explore Transplant Ontario program [12,78,91]. Future studies are needed to demonstrate if tailored LDKT education programs outside the transplant centers [37,43,54,78,88] may improve access to LDKT.

Strengths of our study include the relatively large sample size, detailed clinical and sociodemographic variables, and a long follow-up period. We do acknowledge, however, that this work has important limitations, as well. First, our data is generated from a single-center in Canada, which may limit generalizability of the findings. Furthermore, the number of participants in each ethnic minority group was relatively small. However, our sample is ethnically and culturally diverse. Second, ethnic background was not self-identified. We are also aware that ethnocultural categories used in this study are not homogenous; however, we could not analyze more granular categories (Indigenous Peoples, Middle-Easterns, etc.), given the small number of these patients in our sample. Moreover, we did not have data about the ethnicity of the potential donors, therefore, we could not assess if discordant ethnicity of the donor–recipient pair was associated with different likelihood of achieving LDKT. Third, we did not know how many attempts patients may have taken to find a LD prior to the pretransplant assessment. In this study, we assumed that patients who stated they had a potential LD identified were at a more advanced stage of LDKT readiness; however, this may not be true for all cases. However, in an ongoing mixed methods study assessing ethnocultural barriers to LDKT, we found that compared to Caucasians, both African and Asian Canadian patients on dialysis were less willing to take small steps toward LDKT [35,44,45,63] supporting the interpretation of our results in this manuscript. Fourth, we did not have information about the number of years a patient had lived in Canada, primary language, health literacy, religious affiliation, culturally defined health related beliefs, HLA type, immigration status or social support. However, in a recent preliminary analysis of an ongoing study, [92] we found that only a few of the patients in that sample were recent immigrants to Canada; consequently, we think that this confounder was unlikely to significantly change the results in this study. Another limitation of our study is that we do not know if patients from minority groups may face any potential referral barriers in their renal programs. Data about ethnicity/race is not collected systematically in our healthcare system, therefore, we do not have accurate information about the ethnic composition of the dialysis population in Ontario. Finally, despite adjusting for a number of sociodemographic and clinical covariates, residual confounding cannot be entirely excluded.

We conclude that compared to Caucasians, African Canadians, East and South Asians are less likely to have a potential LD identified at the first pretransplant assessment. Patients who did not have a potential LD identified at the first pretransplant assessment were substantially less likely to receive a LDKT during the subsequent years. Further research is needed to understand the underlying barriers and causes of ethnic inequities in access to LDKT in Canada, and to demonstrate if improved culturally competent LDKT education throughout illness trajectory will reduce the documented ethnic inequities.

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Authorship

IM, OF, MN: research design. AB, MM, PY and OF: data acquisition. AB, OF: data analysis. IM, MN, ADW, and SJK: supervision and mentorship. IM, AV, AB, MM, MN, ADW, SS, and SJK: interpretation of data. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

Disclosures

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Figure S1. Cumulative probability of receiving a deceased donor kidney transplant in those with no potential living donor identified versus having a potential living donor identified at the time of first pretransplant assessment.

Table S1. Baseline characteristics by "having a potential living donor identified" at the time of first pretransplant assessment (yes/no).

Table S2. Median time (days) from referral to the transplant program to receiving a transplant for various groups.

Table S3. The proportion of patients with versus without a potential LD at presentation receiving LDKT among the various ethnic groups.

Table S4. Competing risk analysis of receiving LDKT, DDKT, or any KT when the competing event is "death" for patients who did not have "a potential living donor identified" at the time of first pretransplant assessment.

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