



Compatible Donor and Recipient Pairs' Perspectives on Participation in Kidney Paired Donation Programs: A Mixed-Methods Study

Canadian Journal of Kidney Health and Disease
Volume 8: 1–16
© The Author(s) 2021
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/20543581211058932
journals.sagepub.com/home/cjk



Marie-Chantal Fortin^{1,2,3} , John Gill⁴, Julie Allard^{1,2}, Fabián Ballesteros Gallego^{1,2}, and Jagbir Gill^{2,4}

Abstract

Background: Compatible pair participation in kidney paired donation (KPD) may increase the likelihood of finding suitable matches for all registered pairs. Retrospective studies have shown variable enthusiasm for participating in KPD in compatible pairs.

Objective: The study objective was to gather potential living donor (PLD) and transplant candidate (TC) perspectives on compatible pair participation in KPD.

Design: Surveys and qualitative interviews.

Setting: Three transplant programs in Canada: Centre hospitalier de l'Université de Montréal in Montreal (Québec), Vancouver General Hospital, and St. Paul's Hospital in Vancouver (British Columbia).

Patients: Both PLDs and TCs undergoing evaluation for donation/transplantation between 2016 and 2018 at 3 transplant programs in Canada.

Methods: Descriptive statistical analysis was performed for the results of the survey and thematic and content analysis method was used for the content of the qualitative interviews.

Results: A total of 116 PLDs and 111 TCs completed surveys and an additional 18 PLDs and 17 TCs underwent semi-directed interviews. Of those surveyed, 61.2% of PLDs and 76.6% of TCs reported a willingness to participate in KPD as a compatible pair. The possibility of a more optimally matched kidney for the TC and policies ensuring prioritization of the TC for repeat transplantation in the event of early graft failure increased willingness to participate in KPD. Major concerns expressed during the interviews included the desire to retain the emotional bond of directed donation, the fear of chain breaks or donor renegeing, delays in transplantation, and additional travel associated with participation in KPD.

Limitation: The limitations of this study are that it was conducted in only 3 Canadian transplant programs and that the interviews and surveys were in French and in English. As a consequence, the results may not be reflective of the views of individuals not living in these 2 provinces and from ethnic minority populations.

Conclusion: Most of the compatible PLDs and TCs surveyed were willing to participate in KPD. Ensuring timely transplantation and a more optimal match for TCs and offering a policy of reciprocity to ensure timely repeat transplantation for compatible recipients if their allograft fails post KPD transplant may further increase compatible pair participation in KPD.

Abrégé

Contexte : La participation de paires d'individus compatibles au don croisé d'un rein (DCR) peut augmenter la probabilité de trouver des donneurs et receveurs compatibles pour tous les individus enregistrés. Des études rétrospectives ont montré un enthousiasme variable des paires d'individus compatibles à participer au DCR.

Objectifs : Cette étude visait à recueillir les points de vue de donneurs vivants potentiels et de candidats à la greffe sur la participation de paires d'individus compatibles au DCR.

Type d'étude : Sondages et interviews qualitatives.

Cadre : Trois programmes de transplantation canadiens : le centre hospitalier de l'Université de Montréal à Montréal (Québec), de même que le Vancouver General Hospital et le St Paul's Hospital de Vancouver (Colombie-Britannique).

Sujets : Les donneurs vivants potentiels (DVP) et les candidats à la greffe (CG) ayant fait l'objet d'une évaluation pour un don ou une transplantation dans trois programmes de transplantation canadiens entre 2016 et 2018.



Méthodologie : Une méthode d'analyse statistique descriptive a servi à analyser les résultats du sondage, tandis que le contenu des interviews qualitatives a été analysé à l'aide de méthodes d'analyse thématique et de contenu.

Résultats : En tout, 116 DVP et 111 CG ont répondu au sondage, alors que 18 DVP et 17 CG supplémentaires ont été rencontrés pour des entrevues semi-dirigées. Parmi les répondants au sondage, 61,2 % des DVP et 76,6 % des CG ont indiqué qu'ils seraient prêts à participer au DCR en tant que membre d'une paire d'individus compatibles. La possibilité pour le CG d'obtenir un rein avec un meilleur match et les politiques assurant la priorisation du CG pour une transplantation répétée en cas d'échec précoce de la greffe ont augmenté la volonté de participer au DCR. Parmi les principales préoccupations exprimées au cours des entrevues figuraient notamment le désir de préserver le lien émotionnel du don dirigé, la peur d'une rupture dans la chaîne, la peur du renoncement du donneur, les possibles retards pour la transplantation et les déplacements supplémentaires associés à une participation au DCR.

Limites : L'étude est limitée par le fait qu'elle n'a été réalisée que dans trois programmes canadiens de transplantation et que les entrevues et les sondages n'étaient menés qu'en français et en anglais. Les résultats pourraient par conséquent ne pas refléter les opinions des personnes issues des minorités ethniques ou ne résidant pas dans ces deux provinces.

Conclusion : La majorité des DVP et des CG compatibles qui ont été interrogés étaient ouverts à participer au don croisé d'un rein. Il est possible d'augmenter la participation de paires d'individus compatibles au don croisé d'un rein. Pour ce faire, on doit assurer une par un meilleur match optimale et une greffe en temps opportun pour les candidats à la transplantation; il faut également offrir une politique de réciprocité assurant une greffe répétée en temps opportun aux receveurs compatibles dont l'allogreffe échoue après un DCR.

Keywords

kidney paired donation, compatible pairs, survey, qualitative interviews, reciprocity

Received April 30, 2021. Accepted for publication September 23, 2021.

Introduction

Kidney paired donation (KPD) is a strategy for enabling living-donor kidney transplantation (LDKT) by matching incompatible pairs. In Canada, the national KPD program was developed in 2009.¹⁻³ As of December 10, 2020, 765 kidney transplantations had been performed through the Canadian KPD program.² Despite the successes of KPD programs, some incompatible pairs are unable to find a match: only 38% of recipients with a blood group-incompatible donor and 45% of recipients with an HLA-incompatible donor have been transplanted in Canada's national program.³

Increasing the number of registered pairs significantly improves the yield from KPD by increasing the percentage of registry matches, particularly among the most difficult-to-transplant candidates.^{4,5} In 2010, Ratner and colleagues first described the participation of 2 compatible pairs in a kidney chain and reported a certain ambivalence toward participating as a compatible pair in KPD.⁶ In 2012, Bingaman et al⁷ reported the participation of 17 compatible pairs in their kidney exchange programs, and, more recently, Weng et al⁸

described the participation of 11 compatible pairs in their single-center KPD program.

In Canada, there are no current recommendations to guide the participation of compatible pairs in KPD.⁹ A survey of prior living kidney donors and transplant recipients in British Columbia (BC) showed that more than 90% of living donors and transplant recipients were willing to participate as compatible pairs in KPD.¹⁰ However, these data are limited by the fact that those individuals had already successfully donated or received a transplant and were commenting on a hypothetical scenario. Their past experience with donation could create a cognitive bias in favor of participation in KPD. Also, participants in this study did not have the opportunity to explain in-depth their perspectives and rationale behind their willingness, or lack of willingness, to participate. No study has prospectively explored the perspectives of potential Canadian potential living donors (PLDs) who have not yet donated and TCs who have not yet received a transplantation on the participation of compatible pairs in KPD. Their perspectives are of paramount importance in designing or implementing an acceptable program for them. The objective

¹Centre de recherche du Centre hospitalier de l'Université de Montréal, QC, Canada

²Canadian Donation and Transplantation Research Program, Edmonton, AB, Canada

³Faculty of Medicine, Université de Montréal, QC, Canada

⁴Faculty of Medicine, The University of British Columbia, Vancouver, Canada

Corresponding Author:

Marie-Chantal Fortin, Centre de recherche du Centre hospitalier de l'Université de Montréal, 900 Saint-Denis Street, Room 12-418, Montréal, QC H2X 0A9, Canada.

Email: marie-chantal.fortin.med@ssss.gouv.qc.ca

of this study was to use mixed methods (through surveys and qualitative interviews) to prospectively gather PLD and transplant candidate (TC) perspectives on participating in KPD as compatible pairs, to inform the feasibility of enrollment of compatible pairs in KPD and the development of national policies in the Canadian KPD program.

Materials and Methods

Mixed methods were used to prospectively assess the views of TCs and PLDs who were undergoing evaluation for compatible LDKT (but had not yet donated or received a transplant) at 3 large Canadian kidney transplant centers—Vancouver General Hospital and St. Paul's Hospital in Vancouver, BC, and the Centre hospitalier de l'Université de Montréal (CHUM) in Montréal, Quebec—between June 2016 and August 2018. Quantitative surveys and qualitative interviews were conducted sequentially to gain in-depth insight on participants' attitudes toward participation in KPD.¹¹ Patients were recruited from these 2 provinces to capture the diversity of opinions from 2 regions with very different rates of living donation, BC having one of the highest rates of living donation in Canada, and Quebec having among the lowest. During the study period, there was no standardized approach or education in any of the centers with respect to the participation of compatible pairs in KPD. The CHUM and UBC Providence Health REBs approved the study and all participants provided informed consent.

Adult TCs and PLDs who were medically approved or were within the final stages of evaluation for transplantation or donation with a compatible PLD or TC were included in the study. TCs and PLDs who were working toward a compatible transplant but were unaware of their compatibility at the time of the interview were also included. Incompatible pairs, nondirected anonymous PLDs, and TCs with out-of-country PLDs were excluded.

Surveys

A published survey of prior living donors and transplant recipients on enrollment in KPD was modified for this study.¹² The final survey consisted of questions in multiple-choice format and short forced-choice questions using 3- and 5-point Likert scales. Separate surveys were developed for PLDs and TCs and were translated in English and French (see Supplementary file for full surveys). The survey questions captured key sociodemographic and disease-related characteristics (for TCs) and addressed the following themes: (1) willingness to participate as a compatible pair in KPD, (2) facilitating factors and barriers to participating as a compatible pair in KPD, and (3) the decision-making process to consider enrollment in KPD as a compatible pair. In addition, a self-reported altruism (SRA) scale¹³ was used to account for the level of altruism in survey respondents. Survey questions were pilot-tested with 6 past living kidney donors and

6 transplant recipients (evenly distributed between English- and French-speaking). Both PLDs and TCs were invited to participate in the survey during their pre-assessment medical visits between June 2016 and July 2017, and completed the surveys anonymously thereafter.

Descriptive statistical analyses were performed to characterize each group in terms of age, gender, socioeconomic status, race/ethnicity, blood type, relationship to directed donor/recipient, SRA score, and dialysis status and duration (for TCs). The willingness of TCs and PLDs to participate in KPD as a compatible pair overall and under specific circumstances was described by reporting the proportion of participants who responded to each category of willingness in the Likert scale. Continuous variables were reported as means and standard deviations, whereas categorical variables were reported as proportions. Comparisons between groups were made using a chi-squared test and *t* test, as appropriate. Statistical analyses were performed using R v3.4.4 (2018-03-15).

Qualitative Interviews

Convenience sampling¹⁴ was used to recruit PLDs and TCs to gain further insight into participants' views on the participation of compatible pairs in KPD. Participants were invited to take part in semi-directed interviews between May 2017 and August 2018. Twenty-nine TCs and 16 PLDs attending the CHUM and 42 TCs and 24 PLDs attending BC transplant clinics were approached by transplant nurses, transplant coordinators, or a receptionist and received an invitation letter to participate in this project. Among the 66 PLDs and TCs from BC, 18 were no longer eligible by the time they were contacted because they had either received a transplant or donated, 23 could not be reached, and 25 agreed to participate. Among the 45 PLDs and TCs from the CHUM, 18 were ineligible because they had received a transplant, donated or were no longer suitable for kidney transplantation or donation, and 13 could not be reached. Fourteen participants from the CHUM were contacted, of which 4 declined the invitation and 10 agreed to participate. Three interviews were conducted in person and 32 by phone by a member of the research team (F.B.G.). Twenty-six interviews were conducted in English and 9 in French. The interviews lasted roughly 30 minutes (22–45 minutes) and were digitally recorded and transcribed.

The issues covered during the interviews were outlined in an interview guide with open-ended questions that was based on a literature review and the researchers' previous work in the field.^{15–19} It addressed the following themes: (1) attitudes toward participation in KPD, (2) factors that could affect their willingness to participate in KPD, and (3) fears and expectations surrounding KPD (see Supplementary file for interview guide). The interview guide was pilot-tested in English and French by 3 transplant recipients and 1 living donor.

Interview transcripts were analyzed using the content and thematic analysis method described by Miles and Huberman.²⁰ NVivo 11 (QSR International) computer software was used to facilitate the qualitative analysis. Two members of the research team developed the coding frame (M-C.F. and F.B.G.) based on the interview topics. A deductive approach to coding was used, but new codes were also generated based on new themes that emerged during the analysis. However, F.B.G. coded all the interviews. The number of participants allowed for data saturation.¹⁴ No new codes were created after the 31st interview. An independent researcher with experience in qualitative methods and research in the field of organ transplantation (J.A.) coded 17% of the raw data, and the rate of coding agreement was subsequently assessed at 96%. We used the consolidated criteria for reporting qualitative research checklist.^{14,21}

Results

Participant Characteristics

Tables 1 and 2 outline the characteristics of the TCs and PLDs who completed the survey or interviews. A total of 111 TCs and 116 PLDs completed the survey, and 17 TCs and 18 PLDs took part in in-depth interviews.

Willingness to Enroll in KPD

Survey results. Seventy-one of PLDs surveyed (61.2%) and 85 of TCs surveyed (76.6%) reported a willingness to enroll in KPD as a compatible pair (Table 3). Table 3 outlines surveyed TC and PLD characteristics by their willingness to enroll in KPD as a compatible pair. Among TCs who were unwilling to enroll in KPD, there was a higher proportion of individuals who had a spousal potential donor, a university or college education, and a higher income. Dialysis exposure was also lower among TCs who reported an unwillingness to enroll in KPD. Among PLDs who were unwilling to participate in KPD, there was a higher proportion of individuals who were spouses or biological relatives of their intended recipient, but all other characteristics were not significantly different from those of PLDs who were willing to participate in KPD. The SRA score was not significantly different between groups.

Qualitative interviews. Two PLDs (11.1%) and 8 TCs (47.1%) interviewed were willing to participate as compatible pairs in KPD, citing the following reasons: to increase the number of transplantations performed, to help other people, and because of the possibility of the TC receiving a younger, better-matched and healthier kidney that will last longer. That being said, PLDs and TCs who were willing to participate in KPD as compatible pairs wanted assurance that the TC would receive a kidney transplant.

For most of the TCs and PLDs who were unwilling to participate or ambivalent about participating as compatible pairs in KPD, the main reason cited was the established relationship with the PLD or TC or their not knowing the donor or recipient personally. Some recipients pointed to the emotional nature of living kidney donation and the difficulty of donating an organ to a stranger, whereas others indicated that they want to donate to their intended recipient because they know them and decided to donate to this person and no one else. Transplant candidates also mentioned being more comfortable receiving a kidney from a compatible person they know than from a stranger. Some participants also needed more time to consider this option. Table 4 summarizes the themes and presents interview excerpts.

Factors That Influence Willingness to Enroll in KPD

Survey results. The vast majority of PLDs (87.1%) and TCs (85.4%) felt the decision to enroll in KPD should be shared between the PLD and TC (Tables 5 and 6). When asked which single factor most increased willingness (Figure 1), the largest group of PLDs (67%) reported getting a “better kidney” for their intended recipient, whereas 38% of TCs reported getting a “better kidney” as the most important factor in their decision-making. However, more TCs (39%) reported wanting to help as many other people as possible as the most important factor. Conversely, ending up with a “lesser quality kidney” for the recipient was the most important factor that would deter PLDs and TCs from pursuing compatible KPD, with 56% of PLDs and 48% of TCs reporting this as the most important factor (Figure 2).

Importantly, 47.4% of PLDs and 61.3% of TCs reported no change to their willingness to consider KPD if there was no clear medical benefit for the intended compatible TC. Furthermore, 58.6% of PLDs and 54.1% of TCs reported an increased willingness if they could facilitate one additional transplant for a stranger and an even greater proportion reported an increased willingness if transplantation facilitated more than one extra transplant. Facilitating transplantation for a minor or for someone else they knew also increased willingness to participate in KPD. Similarly, having the option to meet the individual that compatible KPD benefited increased willingness to participate in both PLDs and TCs, although most (84.4%) of PLDs stated their willingness to participate was unchanged even if they were to remain anonymous.

Prioritization of the compatible TC for repeat transplantation in the event that the KPD transplant fails significantly increased the willingness of compatible PLDs and TCs to participate in KPD, with 72.4% of PLDs and 80.2% of TCs reporting an increased willingness to enroll in KPD if there were a policy of reciprocity, whereby if the TC’s transplant from KPD were to fail within the first year, they would be

Table 1. Survey Respondents' Characteristics.

	Transplant candidates N = 111	Potential living donor N = 116
Sex		
Male	69 (62.2%)	52 (44.8%)
Female	41 (36.9%)	64 (55.2%)
Missing	1 (0.9%)	0
Median age	49 (38-62)	47.5 (38-59)
Race		
Aboriginal	7 (6.3%)	5 (4.3%)
Asian	14 (12.6%)	14 (12.1%)
White	84 (75.7%)	85 (73.3%)
Other	4 (3.6%)	11 (9.5%)
Missing	2 (1.8%)	1 (0.9%)
Education		
High school or less	44 (39.6%)	25 (21.6%)
University/College or greater	66 (59.5%)	91 (78.5%)
Missing	1 (0.9%)	0
Household income		
Less than US\$15 000	12 (10.8%)	1 (0.9%)
US\$15 000 to US\$30 000	14 (12.6%)	8 (6.9%)
US\$30 000 to US\$50 000	16 (14.4%)	17 (14.7%)
US\$50 000 to US\$100 000	37 (33.3%)	39 (33.6%)
US\$100 000 and more	19 (17.1%)	47 (40.5%)
Missing	13 (11.7%)	4 (3.5%)
Employment		
Employed	47 (42.3%)	92 (79.3%)
Retired	31 (27.9%)	18 (15.5%)
Unemployed	29 (26.1%)	4 (3.5%)
Other (homemaker, student)	2 (1.8%)	2 (1.7%)
Missing	2 (1.8%)	0
Marital status		
In a relationship	78 (70.3%)	83 (71.6%)
Single/divorced	31 (27.9%)	33 (28.5%)
Missing	2 (1.8%)	0
On dialysis		
Yes	63 (56.8%)	N/A
No	46 (41.4%)	N/A
Missing	2 (1.8%)	N/A
Is your recipient on dialysis?		
No	N/A	43 (37.1%)
Yes	N/A	72 (62.1%)
Missing	N/A	1 (0.9%)
TC transplant wait time, mo	6 (1-24)	6 (3-12)
TC and PLD relation		
Spouse	20 (18.0%)	30 (25.9%)
Related	57 (51.4%)	60 (51.7%)
Unrelated	30 (27.0%)	25 (21.6%)
Missing	4 (3.6%)	1 (0.9%)
SRA	58 (52-67)	63 (55-72)

Note. TC = transplant candidate; PLD = potential living donor; SRA = self-reported altruism; N/A = not applicable.

moved to the top of the wait list for a deceased-donor transplant. Interestingly, extending this benefit to a KPD transplant that fails beyond the first year after transplantation did not substantially increase willingness further.

Reimbursement of the donor's and a companion's travel expenses increased willingness among 66.4% of PLDs and 76.6% of TCs. Similarly, reimbursing lost wages increased willingness in 51.7% of PLDs and 77.5% of TCs. The

Table 2. In-Depth Interview Participants' Characteristics.

	Transplant candidates N = 17	Potential living donor N = 18
Sex		
Male	13 (76.5%)	3 (16.7%)
Female	4 (23.5%)	15 (83.3%)
Mean age (\pm SD)	48.9 \pm 14.2	51.4 \pm 10.3
Prior kidney transplantation	1 (5.9%)	N/A
Transplant candidate ESRD status		
Dialysis	10 (58.8)	N/A
Pre-dialysis	7 (41.2)	
Level of education		
High school or less	3 (17.7)	4 (22.2)
College/University and higher	14 (82.3)	14 (77.8)
Household income		
<US\$50 000	3 (17.6)	3 (16.67)
>US\$50 000	14 (82.4)	15 (83.14)
Relationship with transplant candidate or living donor		
Family member	10 (58.8)	6 (33.3)
Spouse	5 (29.4)	6 (33.3)
Friend, colleague, or acquaintance	1 (5.9)	6 (33.3)
Unknown ^a	1 (5.9)	0 (0.0)

Note. ESRD = end-stage renal disease; TC = transplant candidate; PLD = potential living donor; N/A = not applicable.

^aThis TC's PLD is a member of his entourage, but the PLD wanted to remain anonymous.

promise of overt cash incentives for the PLD increased the willingness among 55.9% of TCs, but only increased willingness among 31.9% of PLDs.

Delays in transplantation reduced willingness among both PLDs and TCs, with a delay of 3 to 6 months reducing willingness among 66.4% of PLDs and 39.6% of TCs, and a delay of 6 months reducing willingness among 76.7% of PLDs and 65.8% of TCs. Twenty-one percent of PLDs and 19% of TCs reported delays in transplantation as the most important factor that would hinder their willingness to enroll in KPD as a compatible pair (Figure 2). Also, the need for donors to travel to another province reduced willingness among 36.2% of PLDs and 28.3% of TCs.

Qualitative interviews. During the interviews, most of the PLDs and TCs felt that the decision to participate in KPD belongs primarily to the PLD, as it is the donor who is making a sacrifice and has the most to lose by participating in KPD. A participant mentioned that the PLD should be given the option of participating in KPD before knowing whether or not they are compatible with their TC. Some TCs also mentioned that PLDs have chosen their intended recipient and that this decision should be respected. Other participants mentioned that the decision to participate as a compatible pair should be made jointly by the PLD and TC. Table 7 summarizes the themes and presents interview excerpts.

Offering priority points for future kidney transplants to recipients who choose to participate in KPD with a compatible donor in the event that a graft fails was identified as a facilitating factor. Either priority points for a deceased-donor

kidney transplant or for an organ from a donor at the end of the chain in KPD would make participants reconsider their stance on participating in KPD as a compatible pair. Financial incentives such as reimbursing travel expenses for a companion for a donor who has to travel to another transplant center, to have support during organ recovery and offset lost income, were cited as factors that would facilitate participation. The PLDs and TCs also suggested that knowing an incompatible pair registered in KPD would make them more inclined to participate in KPD, indicating that it would be easier to donate or accept a kidney from someone they know and whose lifestyle habits they are familiar with. For one PLD, advanced donation was mentioned as a facilitating factor.

Delaying transplantation as a result of participating in KPD was the major concern expressed by PLDs and TCs. The PLDs are concerned about putting the TC's health at risk if the transplantation is delayed. The other major concern or obstacle regarding participation in KPD is the risk of chain breaks. Donors having to travel to the recipient center and the costs associated with doing so are further obstacles to participating in KPD. Moreover, participants are reluctant to travel to the TC's center because they want to stay close to their family for support and do not want to deal with a medical team with which they are unfamiliar and have not yet established trust. Finally, the quality of the kidney obtained through KPD compared with the kidney from a directed donor is also a major concern and could represent an obstacle to participation. Box 1 summarizes facilitating factors and obstacles and presents interview excerpts.

Table 3. Patient Baseline Characteristics Among Survey Respondents, by Willingness to Enroll in KPD as a Compatible Pair.

	Transplant candidates N = 111			Potential living donor N = 116		
	Willing N = 85 (76.6%)	Unwilling N = 25 (22.5%)	P	Willing N = 71 (61.2%)	Unwilling N = 41 (35.3%)	P
Sex			.728			.173
Male	52 (61.2%)	16 (64.0%)		32 (45.1%)	20 (48.8%)	
Female	32 (37.7%)	9 (36.0%)		39 (54.9%)	21 (51.2%)	
Missing	1 (1.2%)	0		0	0	
Median age	47.5 (38-64)	50 (42-60)	.350	48 (38-59)	46 (36-58)	.553
Race			.844			.811
Aboriginal	7 (8.2%)	0		3 (4.2%)	2 (4.9%)	
Asian	10 (11.8%)	4 (16.0%)		7 (9.9%)	7 (17.1%)	
White	63 (74.1%)	20 (80.0%)		54 (76.1%)	27 (65.9%)	
Other	3 (3.5%)	1 (4.0%)		7 (9.9%)	4 (9.8%)	
Missing	2 (2.4%)	0		0	1 (2.4%)	
Education			.254			.334
High school or less	37 (43.5%)	7 (28.0%)		18 (25.4%)	7 (17.1%)	
University/College or greater	47 (55.3%)	18 (72.0%)		53 (74.7%)	34 (82.9%)	
Missing	1 (1.2%)	0		0	0	
Household income			.405			.019
Less than US\$15 000	12 (14.1%)	0		1 (1.4%)	0	
US\$15 000 to US\$30 000	13 (15.3%)	1 (4.0%)		3 (4.2%)	3 (7.3%)	
US\$30 000 to US\$50 000	11 (12.9%)	5 (20.0%)		11 (15.5%)	6 (14.6%)	
US\$50 000 to US\$100 000	27 (31.8%)	9 (36.0%)		19 (26.8%)	18 (43.9%)	
US\$100 000 and more	14 (16.5%)	5 (20.0%)		34 (47.9%)	13 (31.7%)	
Missing	8 (9.4%)	5 (20.0%)		3 (4.2%)	1 (2.4%)	
Employment			.686			.275
Employed	36 (42.4%)	11 (44.0%)		61 (85.9%)	29 (70.7%)	
Retired	23 (27.1%)	8 (32.0%)		7 (9.9%)	9 (22.0%)	
Unemployed	23 (27.1)	5 (20.0%)		2 (2.8%)	2 (4.9%)	
Other (homemaker, student)	2 (2.4%)	0		1 (1.4%)	1 (2.4%)	
Missing	1 (1.2%)	1 (4.0%)		0	0	
Marital status			.273			.100
In a relationship	57 (67.1%)	20 (80.0%)		53 (74.7%)	29 (70.7%)	
Single/Divorced	27 (31.8%)	4 (16.0%)		18 (25.4%)	12 (29.3%)	
Missing	1 (1.2%)	1 (4.0%)		0	0	
On dialysis			.033			N/A
Yes	53 (62.4%)	9 (36.0%)		N/A	N/A	N/A
No	30 (35.3%)	16 (64.0%)		N/A	N/A	N/A
Missing	2 (2.4%)	0		N/A	N/A	N/A
Is your recipient on dialysis?			N/A			.780
No	N/A	N/A	N/A	27 (38.0%)	14 (34.2%)	
Yes	N/A	N/A	N/A	43 (60.6%)	27 (65.9%)	
Missing	N/A	N/A	N/A	1 (1.4%)	0	
TC transplant wait time, m	6 (1.5-24)	6 (1-12)	.065	6 (3-12)	6 (4-12)	.769
TC and PLD relation			.331			.540
Spouse	12 (14.1%)	8 (32.0%)		17 (23.9%)	12 (29.3%)	
Related	45 (52.9%)	11 (44.0%)		35 (49.3%)	23 (56.1%)	
Unrelated	24 (28.2%)	6 (24.0%)		19 (26.8%)	5 (12.2%)	
Missing	4 (4.7%)	0		0	1 (2.4%)	
SRA	57 (52-67)	61 (55-66)	.616	64 (56-74)	58 (53-71)	.774

Note. KBD = kidney paired donation; TC = transplant candidate; PLD = potential living donor; SRA = self-reported altruism; N/A = not applicable.

Table 4. Reasons Supporting Willingness and Unwillingness to Participate as a Compatible Pairs in KPD.

Themes and interview excerpts	TCs N = 17	PLDs N = 18
Willingness to participate		
Increasing the number of transplantations performed <i>I don't care whether I get it from my wife or somebody else. If you can involve more people, so much the better. . . . It's still to expand the program from an altruistic point of view; it's a good idea because you can involve more people. (TC6)</i> <i>I think we've got to look at all options, and if more people can get kidneys, I think it's a win-win. (PLD3)</i>	4	3
Assurance that the intended recipient will receive an organ <i>Honestly, I'd have no problem with it. What's important is for everyone to have a chance at getting a kidney. And if the donor agrees with that, I have zero problems with it. (TC17)</i> <i>I still would do it, as long as my intended recipient was getting a kidney. (PLD12)</i> <i>But as long as he would get the kidney. I would only do that if he was guaranteed the kidney that they were still a shared pair. (PLD18)</i>	4	2
Obtaining a better kidney for the TC <i>If they could come back to me and they could say, "If you did the living donor paired exchange, there would be a better chance [of your recipient's] transplant being healthier or lasting longer," then I think that might push me in that direction. (PLD1)</i> <i>Open if better organ or clear benefits of it: I would be up to hearing more about it, because if he could receive one that was even better than mine, I would be all for that. (PLD4)</i>	1	4
Unwillingness to participate		
Established relationship between the pair <i>My donor is a relative—my brother—so we have a pretty close bond. I think we would probably have . . . I guess I shouldn't speak for him, but I would probably be a little bit apprehensive about that. (TC2)</i> <i>I have an emotional connection with the person giving me the kidney; I would like it to go to me, and not to someone else. (TC4)</i> <i>I am a blood relative to the person that's receiving my kidney; to me, that makes more sense than anybody else in the world. (PLD3)</i>	8	13
Unwillingness to donate to or receive from a stranger <i>I know [my donor], so for me, it's easier, because I think it's easier than to take a kidney from someone who I don't know what kind of life they've led before me. (TC5)</i> <i>I think, just in general, donors would be a little bit more reluctant to donate to someone they didn't know at all, to a family member or loved one or friend or something like that. (TC9)</i> <i>For now, I feel that I prefer to give the kidney to someone I know, someone I know very well. (PLD15)</i>	9	4
Needing more time to make a decision <i>I would need more time to think about it, only because I was in on the final testing with my nephew when I heard about it. So personally, I would need more time. (PLD5)</i> <i>Those are all really important things to consider. Each one of those aspects of it can change a person's thinking. I think probably I should just sit on it a bit. (PLD6)</i>	1	7

Note. KBD = kidney paired donation; TC = transplant candidate; PLD = potential living donor.

Symbolic Nature of Living Kidney Donation

This topic was only addressed during interviews. Many TCs and PLDs mentioned that there was a difference between directed living kidney donation and donating to a stranger. One PLD who is donating to his or her partner mentioned that there was something special in giving that person something another person could not, whereas another participant mentioned that there is a special connection between donors and their intended recipients, and that the connection is not there if you donate to a stranger. For TCs who participated in

this study, it is important to know the lifestyle habits of the PLD who will ultimately donate a kidney, to be sure that the kidney is of good quality. Another difference between directed LDKT and participation as a compatible pair in KPD is that, in KPD, the PLDs know the TCs and can be sure that the medical condition is not self-inflicted.

Some participants, mostly TCs and some PLDs, indicated that it would make no difference if they received a kidney from a stranger rather than their intended donor. One PLD claimed that if the TC receives a kidney, it does not matter to whom the donor donates, whereas another PLD said that what matters is that the TC receives the best kidney, no

Table 5. Factors Modifying Willingness of PLDs to Participate in KPD as a Compatible Pair.

Factors	Potential living donor N = 116			
	Unchanged	More willing	Less willing	Missing
Benefits for TCs				
There are some advantages for my recipient	15 (12.9%)	101 (87.1%)	0	0
There are no advantages for my recipient	55 (47.4%)	3 (2.6%)	(50.0%)	0
My recipient will receive a kidney with a better match	10 (8.6%)	104 (89.7%)	(1.7%)	0
My recipient will receive a kidney from a younger donor	71 (61.2%)	41 (35.3%)	4 (3.5%)	0
My recipient will be prioritized in the KPD to help them find a match quickly	25 (21.6%)	90 (77.6%)	0	0
Benefit to others				
I will facilitate one extra person being transplanted	46 (39.7%)	68 (58.6%)	1 (0.9%)	(0.9%)
I will facilitate more than one extra transplant	35 (30.2%)	75 (64.7%)	5 (4.3%)	1 (0.9%)
Characteristics of KPD recipient				
The other recipient is someone I know (eg, from dialysis)	64 (55.2%)	50 (43.1%)	(1.7%)	0
The other recipient is from the same cultural background/religion	110 (94.8%)	5 (4.3%)	(0.9%)	0
The other recipient is a minor (<18 years old)	61 (52.6%)	50 (43.1%)	(4.3%)	0
The other recipient is older (>65 years old)	84 (72.4%)	8 (6.9%)	24 (20.7%)	0
The other recipient is in a different province	96 (82.8%)	3 (2.6%)	17 (14.7%)	0
Anonymity				
I will remain anonymous to my recipient in the KPD	97 (84.4%)	11 (9.6%)	(6.1%)	0
I am given the option to meet the other recipient and/or donor after donation	77 (66.4%)	31 (26.7%)	8 (6.9%)	0
Reciprocity for TC				
If my recipient's kidney transplant fails within the first year after transplantation, she or he will be put on the top of the deceased donor transplant wait-list because she/he agreed to go into the KPD as a compatible pair	31 (26.7%)	84 (72.4%)	1 (0.9%)	0
If my recipient's kidney transplant fails within the first 10 years after transplantation, she/he will be put on the top of the deceased donor transplant wait-list because she/he agreed to go into the KPD as a compatible pair	36 (31.0%)	78 (67.2%)	2 (1.7%)	0
If my recipient's kidney transplant fails at any time (including more than 10 years after the transplant), I will be put on the top of the deceased donor transplant wait-list because I agreed to go into the KPD as a compatible pair	34 (29.3%)	80 (69.0%)	2 (1.7%)	0
Financial considerations for PLD				
Travel expenses for myself and <i>one</i> travel partner are covered if I have to travel to another province to donate	36 (31.0%)	77 (66.4%)	3 (2.6%)	0
Travel expenses for myself and <i>more than one</i> travel partner are covered if I have to travel from another province	67 (57.8%)	46 (36.7%)	3 (2.6%)	0
My income lost due to time off work is partially reimbursed	48 (41.4%)	60 (51.7%)	6 (5.2%)	2 (1.7%)
My income lost due to time off work is fully reimbursed	50 (43.1%)	63 (54.3%)	1 (0.9%)	2 (1.7%)
I am given extra money on top of my lost income from taking time off work	71 (61.2%)	37 (31.9%)	6 (5.2%)	2 (1.7%)
Donor travel				
I have to go to another hospital for surgery but stayed in the same city	97 (83.6%)	10 (8.6%)	9 (7.8%)	0
I have to travel to another province to donate	68 (58.6%)	5 (4.3%)	42 (36.2%)	1 (0.9%)
Delays in transplantation				
The transplant had to be delayed less than a month	91 (78.5%)	14 (12.1%)	9 (7.8%)	2 (1.7%)
The transplant had to be delayed between 1 and 3 mo	76 (65.5%)	6 (5.2%)	32 (27.6%)	2 (1.7%)
The transplant had to be delayed between 3 and 6 mo	35 (30.2%)	2 (1.7%)	77 (66.4%)	2 (1.7%)
The transplant had to be delayed more than 6 mo	24 (20.7%)	2 (1.7%)	89 (76.7%)	1 (0.9%)

Note. PLD = potential living donor; KPD = kidney paired donation; TC = transplant candidate.

Table 6. Factors Modifying Willingness of TCs to Participate in KPD as a Compatible Pair.

Factor	Transplant candidate N = 111			
	Unchanged	More willing	Less willing	Missing
Benefits for TCs				
There are some advantages for myself	31 (27.9%)	77 (69.4%)	(2.7%)	0
There are no advantages for myself	68 (61.3%)	9 (8.1%)	(30.6%)	0
I will receive a kidney with a better match	14 (12.6%)	95 (85.6%)	1 (0.9%)	(0.9%)
I will receive a kidney from a younger donor	57 (51.4%)	52 (46.9%)	2 (1.8%)	0
Benefit to others				
I will facilitate one extra person being transplanted	48 (43.2%)	60 (54.1%)	(2.7%)	0
I will facilitate more than one extra transplant	36 (32.4%)	69 (62.1%)	(5.4%)	0
I will remain anonymous to my recipient in the KPD	92 (82.9%)	11 (9.9%)	8 (7.2%)	0
Characteristics of KPD recipient				
The other recipient is someone I know (eg, from dialysis)	54 (48.7%)	53 (47.8%)	3 (2.7%)	(0.9%)
The other recipient is from the same cultural background/ religion	94 (84.7%)	16 (14.1%)	(0.9%)	0
The other recipient is a minor (<18 years old)	65 (58.6%)	32 (28.8%)	13 (11.7%)	(0.9%)
The other recipient is older (>65 years old)	76 (68.5%)	7 (6.3%)	(25.2%)	0
The other recipient is in a different province	83 (74.8%)	12 (10.8%)	16 (14.4%)	0
Anonymity				
I will remain anonymous to my recipient in the KPD	92 (82.9%)	11 (9.9%)	(7.2%)	0
I am given the option to meet the other recipient and/or donor after donation	59 (53.2%)	49 (44.1%)	2 (1.8%)	1 (0.9%)
Reciprocity for TC				
If my kidney transplant fails within the first year after transplantation, I will be put on the top of the deceased donor transplant wait-list because I agreed to go into the KPD as a compatible pair	21 (18.9%)	89 (80.2%)	1 (0.9%)	0
If my kidney transplant fails within the first 10 years after transplantation, I will be put on the top of the deceased donor transplant wait-list because I agreed to go into the KPD as a compatible pair	27 (24.3%)	81 (73.0%)	3 (2.7%)	0
If my kidney transplant fails at any time (including more than 10 years after the transplant), I will be put on the top of the deceased donor transplant wait-list because I agreed to go into the KPD as a compatible pair	24 (21.6%)	85 (76.6%)	2 (1.8%)	0
Financial considerations for PLD				
Travel expenses for my donor and <i>one</i> travel partner are covered if they have to travel to another province to donate	26 (23.4%)	85 (76.6%)	0	0
Travel expenses for my donor and <i>more than one</i> travel partner are covered if they have to travel from another province	39 (35.1%)	70 (63.1%)	2 (1.8%)	0
My donor's income lost due to time off work is partially reimbursed	22 (19.8%)	86 (77.5%)	22 (19.8%)	0
My donor's income lost due to time off work is fully reimbursed	20 (18.0%)	91 (82.0%)	0	0
My donor is given extra money on top of her/his lost income from taking time off work	43 (38.7%)	62 (55.9%)	6 (5.4%)	0
Donor travel				
My donor has to go to another hospital for surgery but stayed in the same city	90 (81.8%)	12 (10.8%)	(8.1%)	0
My donor has to travel to another province to donate	69 (62.6%)	9 (8.1%)	32 (28.3%)	1 (0.9%)
Delays in transplantation				
The transplant had to be delayed less than a month.	78 (70.3%)	22 (19.8%)	10 (9.0%)	1 (0.9%)
The transplant had to be delayed between 1 and 3 mo	74 (66.7%)	13 (11.7%)	23 (20.7%)	1 (0.9%)
The transplant had to be delayed between 3 and 6 mo	60 (54.1%)	6 (5.4%)	44 (39.6%)	1 (0.9%)
The transplant had to be delayed more than 6 mo	33 (29.7%)	5 (4.5%)	73 (65.8%)	0

Note. TC = transplant candidate; KPD = kidney paired donation; PLD = potential living donor.

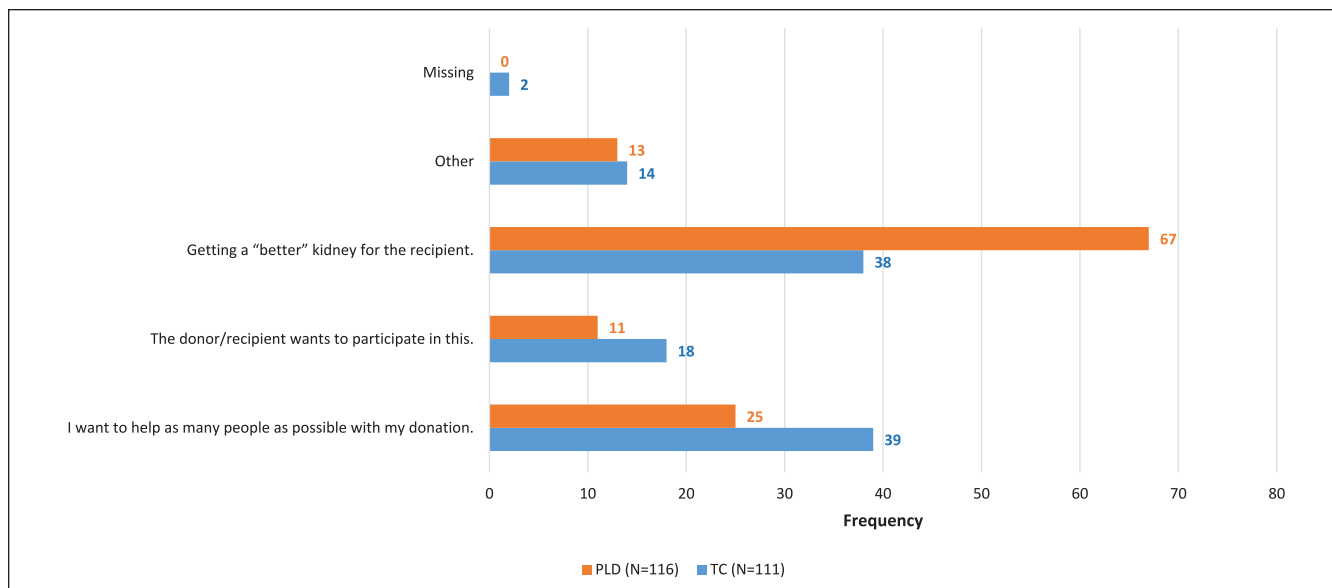


Figure 1. Most important factor that would influence decision to participate in kidney paired donation as compatible pair. Note. PLD = potential living donor; TC = transplant candidate.

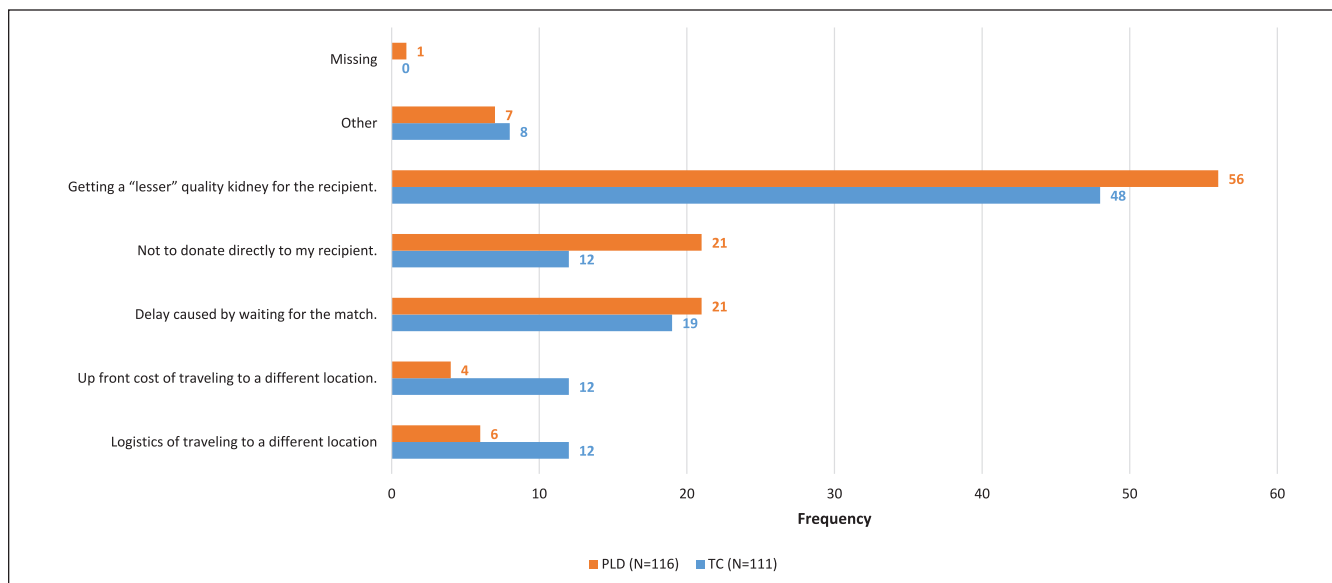


Figure 2. Most important factor that would hinder decision to participate in kidney paired donation as compatible pair. Note. PLD = potential living donor; TC = transplant candidate.

matter who it comes from. Box 2 summarizes the theme and presents interview excerpts.

Discussion

Participation of compatible donor and recipient pairs in KPD continues to be rare, with compatible pairs comprising only 2.3% of transplants performed in the National Kidney Registry in the United States.⁸ In Canada, since the inception of KPD, only 36 compatible pairs have registered in KPD

programs out of a total of 1484 pairs, representing 2.4% of all pairs (Canadian Blood Services, personal communication). In this study, we prospectively examined PLDs' and TCs' perspectives on participation in KPD as a compatible pair, with a cohort of individuals who are actively being evaluated for living kidney donation or transplantation. When surveyed, 61.2% of PLDs and 76.6% of TCs reported a willingness to enroll in KPD as a compatible pair, which is consistent with prior Canadian retrospective survey studies on this issue,¹² but contradicts studies conducted in the United

Table 7. Responsibility for Deciding to Participate in KPD as a Compatible Pair.

Themes and interview excerpts	TCs N = 17	PLDs N = 18
The potential living donor	10	7
<i>I do not feel I am the person that makes that decision, that it should be left up to the donor. (TC3)</i>		
<i>The primary responsibility lies with the donor, because they're doing it obviously for somebody they know or a loved one. (TC6)</i>		
<i>I'm not the one that's giving up a kidney for somebody else. I think that'd be completely up to the person who's donating, unfortunately. (TC9)</i>		
<i>Well, I guess for the recipient, they're in a position where they obviously need a kidney to survive long-term. I'd think it's just a real personal thing with the donor. (PLD5)</i>		
<i>I guess the person who's donating the kidney should make the decision. (PLD6)</i>		
Joint decision between the TC and PLD	7	8
<i>I think it's a decision you make together. So it's not the donor or the recipient, but both. They have to talk about it and make the decision. (TC4)</i>		
<i>I don't know whether it'd be a meeting or a consult or whatever, but I think both of us should be consulted and agree on it. And I know for me, she might say, "Oh, go help that other person," but for me personally, it's . . . really important that she secures what she needs first, if I was going to participate. So that would be my kind of . . . so I don't know how you would decide. I think everyone would have to agree on it. (PLD9)</i>		

Note. KPD = kidney paired donation; TC = transplant candidate; PLD = potential living donor.

States and the Netherlands that reported a higher degree of ambivalence or lack of interest in participating in KPD among compatible pairs.^{6,22} Interestingly, only 11.1% of PLDs and 47.1% of TCs who consented to the in-depth interviews were willing to enroll in KPD. The decreased willingness to participate in KPD reported by individuals who took part in interviews may be attributed to the inherent difference in methodology. The smaller cohort of individuals who consented to interviews may represent a selected subset of individuals who were more concerned about KPD, but it is also possible that TCs and PLDs may have felt more comfortable voicing their concerns in an interview.

Another important consideration is that individuals who completed the surveys were at an earlier phase in their donation and transplantation evaluation process compared with those who completed the interviews. Surveys were all completed among individuals for whom a final decision regarding candidacy had not yet been made, whereas the in-depth interviews were conducted among individuals who were at a later point in their evaluation process where their candidacy had often been finalized and plans were being made in the context of a direct compatible transplant. These results may indicate that compatible pairs of PLDs and TCs may be more inclined to consider KPD at an earlier stage in their evaluation rather than at a later point where plans for directed donation are more firmly established. Therefore, the timing of discussions about KPD for compatible pairs may be a key factor, suggesting that earlier introduction of this option may be preferable, to make TCs and PLDs more comfortable considering this as a viable option and allow them sufficient time to do so.

An important finding in this study is that the prospect of facilitating transplantation among additional patients in and of itself appears to be a strong motivator for TCs to consider

KPD, and, in both surveys and interviews, was cited as the most important factor driving their desire to participate as a compatible pair. As in prior studies,^{6,8,22,23} finding a "better match" or medical advantage for the intended TC was also cited by both PLDs and TCs as an important motivator for participating in KPD and has the potential to further increase willingness to participate as a compatible pair.

The PLDs who participated in our study also wanted to ensure that no harm comes to their intended TCs through the decision to pursue KPD as a compatible pair. In particular, avoiding delays in transplantation that may result in prolonged dialysis exposure and associated harm for the TC was viewed as a key condition for considering participation in KPD. In the Canadian KPD program, there are only 3 match cycles per year to maximize matches, resulting in a median wait time of 182 days from the time of enrollment to transplantation.¹ Consequently, the anticipated delays in large KPD programs like this may limit the opportunities for compatible KPD. Conversely, KPD programs with an increased frequency of match runs are likely to be more suitable for enrollment of compatible pairs in KPD.

Both PLDs and TCs were highly supportive of policies that would ensure rapid access to repeat transplantation for TCs that enroll in KPD with a compatible donor. More than 72% of PLDs and 80.2% of TCs reported an increased willingness to participate in KPD as a compatible pair if there were a guarantee of prioritization for repeat transplantation through either a deceased donor or a nondirected living donor (through KPD) if the transplant recipient suffered allograft loss within the first year following transplantation. Importantly, providing a similar guarantee for recipients' whose graft failed after the first year post-transplant did not further increase willingness to participate in KPD. Therefore,

Box 1. Facilitating Factors and Obstacles to Participation as a Compatible Pair in KPD.

Facilitating factors

Priority points for the donor and/or recipient of the compatible pair

Yeah, that [priority points] would definitely get me more willing to participate. Because to be honest with you, what you just described is what I may need to deal with. I'm only in my 30s, and I'm going through a transplant even in my 30s. Most kidney life only lasts 15 to 20 years. I'm looking at another one probably in my lifetime. So yes, if that was the case that would make me participate probably more actively in your program. (TC7)

I think if you start on that really positive note of, "You go to the top of the list if you've donated and something fails, that you would be, as quick as possible, united with another kidney," because I think that is a game changer. (PLD2)

Reimbursement of expenses for the donor and a companion

That's a great incentive. You need emotional support. I mean, this is not a small thing. You are taking out something out of someone. And you know, it's one thing to stay in the same city as your recipient because, you know, you're close to them, right? But I think the emotional support that they have if they were to leave the city would be a great benefit to the well-being of the person's mental health. (TC16)

That would help to make a decision to go for it, yeah, 'cause you need someone with you, and then if you could have their expenses covered as well, that would just take away some of the burden. (PLD4)

Knowing the other TC or PLD

Well, probably if you knew a bit about the other people's backgrounds, it'd be easier, then, to participate in an exchange like that. (TC5)

I think I'd be very willing to enter the exchange program, but sort of further on my previous comment, I think when there's . . . when you know there's a specific person in need—I mean, everyone's in need—but if you know the person, it just adds that personal connection that I think humans in general respond to emotionally, whether they want to or not. (PLD13)

Advanced donation

One thing that did come into my mind is kind of about timing, because with a direct donation, for me to donate to him, that means that we're both out of commission. Maybe with the living donor paired exchange, I would donate first, and then [name redacted], maybe a few weeks or months later, would get his transplant, and that would enable me to heal. I'd be able to take care of him after he took care of me, so to kind of stagger the caregiving. (PLD1)

Obstacles

Chain breaks and/or donor renegeing

I think it would be breaking the chain. So, let's say you have five lined up, one breaks the chain and then it means all five don't get the kidney, right? So that's one thing that I'm worried about. (TC16)

I don't know if it'd be a selfish concern, but the concern would be that I donate a kidney, and one is not available or does not get donated in return. (PLD5)

And the other concern—and I'm sure this would be very unlikely to happen—but I would want to understand for sure that once I've donated a kidney, that my recipient is also guaranteed to get one, you know, that there's not going to be a point where that other person at the last moment says, "Oh, I changed my mind, I don't want to do this." (PLD8)

I would be concerned about him maybe not receiving a kidney from somebody else. I know with me, I would definitely be following through, and maybe it's just a trust thing. I just don't know whether the program will actually look after him in the future like I could do now. (PLD10)

Donors' travel to another transplant center and associated costs

Him [my donor] taking a week off and then the subsequent recovery time, you know, very tough on his family and on him financially. So I think for some people, that has to be an impediment. (TC6)

My biggest issue would be—and I don't know enough about the program, is my problem, when it comes to the donors themselves—do they have expenses, for instance, of having somebody to come with them, to help them if they need the help? (TC7)

I would just be worried about being away from my family for that long. Then it's starting to have real impacts on me. I'm already missing work, but at least I get to be around my family. I couldn't imagine missing work and being away from my family. (PLD7)

My major concern would be having to travel out of province to do it. There's a few impediments there. First and foremost, it would be cost-prohibitive to me to travel and secure accommodation for a couple of weeks somewhere else. The second is that I have a chronic pain condition that makes travel challenging for me, and I don't have anybody who would be able to go with me and help me out after my surgery. So that's the big issue. (PLD8)

Quality of the donor organ

What happens if he gives a kidney that, he's a fairly young, healthy individual, but what if I get somebody that is a match, that I'm getting somebody's kidney that maybe is even older than my dad's, for instance? . . . What's their health like? What has the individual dealt with in the past? (TC7)

That's most important. I mean, equal or better [kidney] but definitely not inferior. (TC15)

He could receive a good kidney, but it's more like . . . It would be better if the person that I know, who's close to me, had the same kidney, you know, the right kidney, from the same family you might say. (PLD15)

And I'd say the only, the big obstacle I see is really the recipient being penalized. If he loses his donor, he shouldn't lose his chance for a transplant in time and he should receive a good-quality kidney. (PLD17)

Note. KBD = kidney paired donation; TC = transplant candidate; PLD = potential living donor.

Box 2. Symbolic Nature of Living Kidney Donation.

Differences between directed donation and donating to a stranger

Emotional connection between the donor and recipient

You have that connection to the person that you're donating to, whereas someone anonymous, you don't have that connection. (TC2)

I have to admit, though, there is a little bit of an emotional attachment to know that I'm providing something to [my husband] that someone else couldn't provide. (PLD1)

It's a very personal thing to do this, and I'm doing it for my son, and I'm doing it specifically because he [has] special needs, and I'm not convinced that he would be at the top of the list, given other circumstances. (PLD2)

It's within the family, so it's even stronger, which is why I prefer to give it to someone who is very close to me. (PLD15)

The donor sees the recipient's transplantation outcomes

I don't think you give a kidney for the sake of giving a kidney. In reality, you give a kidney because you want to save someone you know. I'm not sure that people are prepared to donate a kidney so that it can be put into a bank. I don't think we're there yet, or not in Canada at least! (TC5)

I mean, it's probably easier to know who you're donating to and know how that kidney is being treated and to know that you have helped to extend the life of someone that you care about. When you're not exactly sure what's happened to your kidney or . . . then it's a bit more of a mystery. (PLD11)

The TC knows the PLD's lifestyle habits

I don't know what the difference is when you have someone who's close to you, you don't know the person, what's his lifestyle, what's his health like, you know if the person's compatible, you know that he takes care of himself like I do, so I wouldn't want a kidney from someone I don't know. (TC4)

The big advantage of getting it from somebody you know is that—I know my wife's lifestyle is . . . her diet is good, her exercise is good, blah, blah, blah. So I have a profile from her that I say, "Yeah, I'm getting it from a very healthy individual." (TC6)

PLD knows that the ESRD is not self-inflicted

The big thing for me was, the donation was made—and maybe this is selfish, I don't know—but if the person had done self-harm through drugs or some form of personal abuse, I would not be as willing to be involved as, certainly in this case, where it's a genetic deal with my recipient. (PLD5)

The only thing I would have a hard time [with] is, not knowing the lifestyle of [the person] who would be getting my kidney. I would have a really hard time donating to someone who had a drinking problem or drug problem or was involved in a bad group of people. If the disease was brought on by something they inflicted on themselves, I would feel frustrated in that sense. For me, I would be more wanting to know a bit about their lifestyle, 'cause that would make me change my mind. (PLD12)

There is no difference between donating to a stranger or a loved one

No, I don't think there's any difference. It's more at the psychological level for the donor and recipient, because a kidney, if it's compatible with one or the other, or in exchange, the kidney is going to work if it's compatible. (TC10)

I don't think there's a difference for me personally. I believe that, you know, it's passing it forward, right? As long as, you know, everything works, I won't have a problem with that. (TC16)

As long as the person that I know who is in need receives a kidney, it makes no difference to me whether it comes from my body or somebody else's. As long as my kidney is going to improve somebody's life, that's good enough. It really doesn't matter to me. (PLD1)

To me, it doesn't matter. What matters most is that my husband gets the best possible kidney for him. It's more him, really, that I want maximum improvement in his quality of life. (PLD14)

Note. TC = transplant candidate; PLD = potential living donor; ESRD = end-stage renal disease.

a policy of reciprocity whereby TCs who enroll in KPD as part of a compatible pair would be prioritized for repeat transplantation in the event of early graft loss may provide additional assurance for compatible pairs considering KPD and significantly increase the likelihood of enrollment in the program. While such a policy would need to consider the views of all patients waiting for a deceased-donor kidney, the impact of such a policy on wait times has been examined and is likely to be minimal due to the low likelihood of early graft loss following LDKT.^{16,24}

The anonymity of KPD is a major barrier for some compatible pairs to overcome, as it minimizes the perceived connection between donors and recipients. The PLDs interviewed who were unwilling to enroll in KPD felt a sense of "loyalty" and an emotional bond in donating directly to their intended recipient. This sentiment was also noted among PLDs who completed the survey, who reported that they would be more willing to participate in KPD if their kidney were allocated to

a minor or someone they knew. Similar findings were reported by Kranenburg et al,²² who reported that, in the Netherlands, the emotional relationship between compatible donors and recipients was the most frequently cited reason for not wanting to participate in KPD as a compatible pair. Anonymity of donor/recipient pairs is a key component of many KPD programs, including the Canadian KPD program. Examining strategies whereby an emotional link may be established between compatible KPD donors and their recipient while maintaining anonymity may increase willingness of compatible pairs to enroll in KPD programs.

While our work represents the only large-scale prospective mixed-methods study examining the enrollment of compatible pairs in KPD, there are important limitations to consider. The study was conducted in 3 transplant programs in 2 Canadian provinces and therefore may only represent the views of PLDs and TCs in these programs and regions. Although the surveys were anonymous, social desirability

bias may still be an important limitation, particularly during the in-depth in-person interviews. The surveys and interviews were conducted in English and French and excluded individuals with other primary languages. Moreover, participants in the survey were primarily white and highly educated. Also, the interviews and surveys revealed that most donors were either the spouse or a family member of the recipient. As a consequence, these data may not be reflective of the views of individuals in other groups, including ethnic minority populations.

Conclusion

The participation of compatible pairs in KPD has the potential to improve access to kidney transplantation for incompatible recipients and further optimize outcomes for compatible TCs. A high proportion of PLDs and TCs in our study were willing to consider KPD as part of a compatible pair, even in the absence of a direct benefit to the recipient. Approaching PLDs and TCs early in their evaluation process, ensuring timely transplantation and a more optimally matched kidney for TCs, and offering a policy of reciprocity to ensure timely repeat transplantation for compatible recipients should their allograft fail post KPD transplant may further increase participation of compatible pairs in KPD.

List of Abbreviations

BC, British Columbia; ESRD, end-stage renal disease; HLA, human leukocyte antigen; KPD, kidney paired donation; LDKT, living-donor kidney transplantation; PLD, potential living donor; TC, transplant candidate.

Authorship

1. Marie-Chantal Fortin participated in research design, in the performance of the research, in data analysis, and in the writing of the manuscript.
2. John Gill participated in research design and the writing of the manuscript.
3. Julie Allard participated in data analysis and the writing of the manuscript.
4. Fabián Ballesteros participated in the performance of the research, in data analysis, and in the writing of the manuscript.
5. Jagbir Gill participated in research design, in the performance of the research and in the writing of the manuscript.

Ethics Approval and Consent to Participate

The Centre hospitalier de l'Université de Montréal (ethics certificate 15.206) and UBC Providence Health (ethics certificate H15-03361) research ethics board approved the study. All participants provided informed consent.

Consent for Publication

All authors consent to publication.

Availability of Data and Materials

The data are available from corresponding author upon reasonable request.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research project was funded by a Biomedical Research Grant from the Kidney Foundation of Canada.

ORCID iD

Marie-Chantal Fortin  <https://orcid.org/0000-0002-8437-0556>

Supplemental Material

Supplemental material for this article is available online.

References

1. Cole EH, Nickerson P, Campbell P, et al. The Canadian kidney paired donation program: a national program to increase living donor transplantation. *Transplantation*. 2015;99(5):985-990.
2. Canadian Blood Services. Kidney paired donation program. <https://professionaleducation.blood.ca/en/organes-et-tissus/programmes-et-services/kidney-paired-donation-kpd-program>. Published 2016. Accessed July 24, 2020.
3. Malik S, Cole EH. Foundations and principles of the Canadian living donor paired exchange program. *Can J Kidney Health Dis*. 2014;1:6.
4. Segev DL. Innovative strategies in living donor kidney transplantation. *Nat Rev Nephrol*. 2012;8(6):332-338.
5. Gentry SE, Segev DL, Simmerling M, Montgomery RA. Expanding kidney paired donation through participation by compatible pairs. *Am J Transplant*. 2007;7:2361-2370.
6. Ratner LE, Rana A, Ratner ER, et al. The altruistic unbalanced paired kidney exchange: proof of concept and survey of potential donor and recipient attitudes. *Transplantation*. 2010;89(1):15-22.
7. Bingaman AW, Wright FH Jr, Kapturczak M, Shen L, Vick S, Murphey CL. Single-center kidney paired donation: the Methodist San Antonio experience. *Am J Transplant*. 2012;12(8):2125-2132.
8. Weng FL, Grogan T, Patel AM, Mulgaonkar S, Morgievlch MM. Characteristics of compatible pair participants in kidney paired donation at a single center. *Clin Transplant*. 2017;31(6):1-9.
9. Canadian Blood Services. Kidney paired donation. 2021. <https://www.blood.ca/en/organs-tissues/living-organ-donation/kidney-paired-donation>. Accessed November 11, 2021.
10. Hendren E, Gill J, Landsberg D, Dong J, Rose C, Gill JS. Willingness of directed living donors and their recipients to participate in kidney paired donation programs. *Transplantation*. 2015;99(9):1894-1899.

11. Sinuff T, Cook DJ, Giacomini M. How qualitative research can contribute to research in the intensive care unit. *J Crit Care.* 2007;22:104-111.
12. Hendren E, Gill J, Landsberg D, Dong J, Rose C, Gill JS. Willingness of directed living donors and their recipients to participate in kidney paired donation programs. *Transplantation.* 2015;99:1894-1899.
13. Rushton JP, Chrisjohn RD, Fekken GC. The altruistic personality and the self-report altruism scale. *Pers Individ Differ.* 1981;2:293-302.
14. Poses RM, Isen AM. Qualitative research in medicine and health care. Questions and controversy. *J Gen Intern Med.* 1998;13(1):32-38.
15. Gill J, Gill J, Ballesteros F, Fortin M-C. Transplant candidates and potential living kidney donors are supportive of reciprocity for transplant candidates who participate in kidney paired donation with a compatible donor. *Am J Transplant.* 2018;18(suppl 4):528-529.
16. Gill J, Tinckam K, Fortin M, et al. Reciprocity to increase participation of compatible living donor and recipient pairs in kidney paired donation. *Am J Transplant.* 2017;17(7):1723-1728.
17. Durand C, Duplantie A, Fortin M-C. Transplant professionals' proposals for the implementation of an altruistic unbalanced paired kidney exchange program. *Transplantation.* 2014;98(7):754-759.
18. Durand C, Duplantie A, Fortin M-C. Transplant professionals' views on the ethical challenges associated with altruistic unbalanced paired kidney exchange. In: Weimar W, Bos MA, Busschbach JJ, eds. *Organ Transplantation: Ethical, Legal and Psychosocial Aspects. Global Issues, Local Solutions.* Lengerich, Germany: Pabst; 2014:118-127.
19. Fortin M-C. Is it ethical to invite compatible pairs to participate in exchange programs? *J Med Ethics.* 2013;39(12):743-747.
20. Miles MB, Huberman MA. *Qualitative Data Analysis: A Source Book of New Methods* Première ed. Newbury Park, CA: Sage; 1984.
21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357.
22. Kranenburg LW, Zuidema W, Weimar W, et al. One donor, two transplants: willingness to participate in altruistically unbalanced exchange donation. *Transpl Int.* 2006;19(12):995-999.
23. Cuffy MC, Ratner LE, Siegler M, Woodle ES. Equipoise: ethical, scientific, and clinical trial design considerations for compatible pair participation in kidney exchange programs. *Am J Transplant.* 2015;15(6):1484-1489.
24. Verbese J, Thomas AG, Ronin M, et al. Early graft losses in paired kidney exchange: experience from 10 years of the National Kidney Registry. *Am J Transplant.* 2020;20(5):1393-1401.