

# Willingness of Directed Living Donors and Their Recipients to Participate in Kidney Paired Donation Programs

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**Background.** Participation of compatible living donors and recipients in kidney paired donation (KPD) could double the number of KPD transplants. We determined the willingness of previous directed donors and their recipients to participate in KPD and identified the association of various factors, including financial incentives, with willingness to participate. **Methods.** Survey of previous directed living kidney donors and their recipients in a single Canadian center between 2001 and 2009. **Results.** Among 207 of 222 eligible living donors contacted, 86 (42%) completed the anonymous survey; 93% (78/86) of donors indicated willingness to participate in KPD if this option had been provided at the time of donation. An increased willingness to participate was reported among the majority of respondents if reimbursements for lost wages and travel expenses were provided; however, cash payments between \$5 000 and \$50 000 had little impact on willingness. Willingness was also increased with an advantage to the recipient (younger donor or better human leukocyte antigen match), whereas delays beyond 3 months and donor travel were associated with reduced willingness to participate. Among 38 recipients approached during routine clinical follow-up visits over a 3-month period, 100% completed the survey, and 36 of 38 (92%) reported they would have been willing to participate in KPD. **Conclusions.** Over 90% of directed donors and recipients were willing to participate in KPD. Reimbursement for the costs of participation and improved efficiency of KPD (i.e., eliminating travel and reducing transplant times), but not cash payments, may increase participation of compatible donors and recipients in KPD.

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The demand for kidney transplantation continues to exceed the availability of transplantable organs, and strategies to increase either living or deceased organ donation are urgently needed. Kidney paired donation (KPD) is an emerging strategy to increase living donor transplantation among end-stage renal disease patients with an ABO blood group or human leukocyte antigen (HLA) incompatible donor. In Canada, KPD facilitated 240 transplants between 2009 and 2013, representing approximately 10% of all living donor transplants in Canada during this period. Despite this

success, not all registered incompatible pairs are able 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 this national program.<sup>1</sup> This is primarily because of blood group imbalance in the pool of incompatible pairs. Blood group O donors are rare in KPD because they only need to enter KPD when there is a positive cross-match with their donor. Therefore, the only opportunity for blood group O recipients to find a match in KPD is with a blood group O donor who is cross-match positive with their recipient or when a nondirected anonymous donor participates in the program.

The inclusion of compatible living donors and their recipients in the KPD program has been suggested as one potential strategy to increase the number of participants in KPD programs. Although participation of compatible pairs with a blood group O donor would have the biggest impact on matching, the participation of compatible pairs where the donor is not blood type O may still increase the likelihood of matching simply by increasing the number of pairs in the program. Gentry and colleagues<sup>2</sup> estimated that participation of compatible pairs in KPD programs could double the likelihood of finding a match. Bingaman and colleagues<sup>3</sup> reported that the inclusion of 17 compatible pairs in their KPD program facilitated the completion of 134 paired donor transplants in their center, and that all recipients with a compatible donor who elected to participate in the KPD program received a transplant from a living donor younger than their directed donor.

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In a study from the Netherlands only 6 of 24 directed donors reported they would or probably would consider participation in KPD.<sup>4</sup> In another study of 53 potential donors in the United States, Ratner et al<sup>5</sup> reported ambivalence toward KPD participation when there was no advantage to the recipient (mean score on 5-point Likert scale,  $2.6 \pm 1.2$ ), but found that willingness to participate was higher if there was an advantage to the recipient, such as receipt of a kidney from younger donor (mean Likert score,  $3.4 \pm 1.0$ ). Together, these studies suggest limited enthusiasm among compatible donor and recipient pairs to participate in KPD.

In a recent survey, 16 of 19 Canadian transplant professionals supported the use of compatible donors in KPD,<sup>6</sup> but concerns regarding implementation, inconvenience, and potentially disadvantaging directed donors were identified. We recently suggested the possibility of additional compensation or even financial incentives to encourage participation of compatible donor and recipient pairs in the Canadian KPD program.<sup>7</sup> In this scenario, payment would be provided to compensate donors for the inconvenience of participation in the program (i.e., for donor travel, time for additional testing, or delays in donor surgery to accommodate the completion of multiple living donor transplants on the same operative day). Providing a financial incentive for participation might even be considered because restricting eligibility to individuals, who had made an a priori decision to donate an organ and had been approved for directed donation, would theoretically limit the risk of undue donor inducement.

The primary objective of this study was to determine the willingness of previous Canadian living kidney donors to participate in KPD with and without the provision of various types of nonmonetary and monetary incentives had the opportunity been available at the time of their donation. The secondary study objective was to ascertain the opinion of a subset of the directed living donor transplant recipients regarding participation in KPD.

## MATERIALS AND METHODS

The study was performed with the approval of our hospital's research ethics board.

### Survey Design and Administration

To develop survey items, we reviewed relevant publications, solicited input from members of our multidisciplinary living donor assessment team, and sought input from previous living kidney donors. Draft donor and recipient surveys were pilot tested among patients and transplant professionals in our center, and feedback was obtained on clarity, brevity, congruency, and relevance of the survey items.

The self-administered, anonymous donor survey was mailed to all 222 previous living kidney donors in our program between 2001 and 2009 who met inclusion criteria (the survey was not sent to donors whose recipients had died or who had emigrated outside the province of British Columbia). The mailing included a letter explaining KPD and a postage paid envelope to return the survey. Participants were provided an opportunity to return a separate post card in order to receive an electronic coffee card in recognition of their participation. To identify participants for the recipient survey, we approached all recipients of a directed living donor kidney only transplant between 2001 and 2009 in our program

who attended an outpatient clinical transplant appointment between July and September 2013.

### Statistical Analysis

Demographic characteristics of donors mailed the survey, and survey respondents were compared using the  $\chi^2$  test or *t* test as appropriate. For the donor survey and the secondary recipient survey, we determined the proportion of participants who selected the various options to individual survey questions.

The minimum survey sample size was informed by the survey of 53 potential living directed kidney donors by Ratner et al,<sup>5</sup> in which the mean score in response to the 5-point Likert scale question "Willing to participate if no advantage for the recipient" was  $2.6 \pm 1.2$ . This was interpreted as ambivalence by the authors, and we estimated this to be equivalent to a 50% willingness to participate in KPD. We hypothesized that a greater proportion (60%) of previous donors would indicate a willingness to participate in KPD had it been offered at the time of their donation. With  $\alpha = 0.05$ , a sample size of 62 participants would provide 80% power to detect a 60% or higher willingness to participate in KPD.

## RESULTS

### Donor Survey

A total of 222 surveys were mailed to previous living kidney donors who met the study inclusion criteria, and 15 surveys were returned with an incorrect address. Of the remaining 207 donors, 86 donors returned the survey (response rate 42%). Compared to the entire eligible donor population, survey respondents were older and more likely to be of white race (Table 1). The majority of respondents had a college or university education and had an annual household income of \$25 000 to \$50 000.

In response to the statement "I would have liked to have been given the option to participate in a KPD program at the time of my donation," 71 of 86 (83%) of previous directed donors agreed and answered "Yes"; whereas 81 of 86 (93%) agreed and answered "Yes" to the statement, "I would have been willing to participate in paired exchange." The level of satisfaction with the donation experience was not associated with willingness to participate in KPD: for example, of the 16 respondents, who were "very unsatisfied" with their donation experience, 100% were willing to participate in KPD, whereas 45 of the 46 respondents, who were "very satisfied," were willing to participate.

Table 2 shows the responses to survey questions to determine the impact of nonmonetary factors on the donors' willingness to participate in KPD. An advantage to the recipient (such as a younger or better HLA-matched donor) was associated with an increased willingness to participate in KPD, but the majority of respondents also reported no change in willingness to participate if there was no advantage to the recipient. The support of the recipient was associated with an increased willingness to participate, whereas helping more than one other person (length of the chain), or having an existing relationship with other recipients were associated with increased willingness, but to a lesser degree. Travel outside of the province was associated with a lower willingness to participate (in Canada shipping of live

**TABLE 1.**  
**Characteristics of donors who responded to survey and comparison to the population of eligible directed living donors who were mailed survey**

Characteristics	Survey respondents	Donors who were mailed survey	P
N	86	222	
Age (mean ± SD)	47 ± 11	45 ± 12	<0.001
Donor/Recipient Relationship:			0.435
Relative	36 (42)	111 (50)	
Spouse	22 (26)	53 (24)	
Other	25 (29)	58 (26)	
Unknown	3 (3)	0	
Race:			<0.001
White	68 (79)	119 (54)	
Asian	8 (9)	19 (9)	
Other/Unknown	10 (12)	75 (37)	
Education:		N/A	
Grade school	1 (1)		
High school	22 (26)		
Trade school	5 (6)		
College/university	54 (63)		
Other/unknown	4 (5)		
Annual household income		N/A	
<\$25,000	5 (6)		
\$25,000–50,000	19 (22)		
> \$50,000	60 (70)		
Unknown	2 (2)		

N and percentages shown unless otherwise indicated. N/A, not available.

donor kidneys between transplant centers in different provinces is not permitted and KPD donors must travel if matched to an out of province recipient). Donors were also less willing to participate if the surgical date would be delayed more than 3 months.

Table 3 shows the association of different types of monetary payments including reimbursements and financial incentives on donor willingness to participate in KPD. Reimbursement of lost income and companion travel expenses were associated with an increased willingness to participate in KPD (currently only donor but not companion travel expenses are reimbursed), whereas compensation for pain and suffering did not change donor willingness to participate in the majority of

**TABLE 2.**  
**Impact of nonmonetary factors on donor willingness to participated in KPD<sup>a</sup>**

	Less willing, %	No change, %	More willing, %
If there was an advantage to recipient <sup>b</sup>	0	19	81
No advantage to recipient	26	71	4
If recipient enthusiastic about KPD	1	40	58
If participation helped more than 1 other person (length of chain)	0	50	50
If existing relationship with other recipient(s)	1	58	41
If required to travel out of province	51	47	3
Delay in surgery of < 1 month	5	86	9
Delay in surgery of 1–3 months	3	77	21
Delay in surgery of 3–6 months	47	50	3

<sup>a</sup> Among 81 donors who indicated they would have been willing to participate in KPD.

<sup>b</sup> Examples included a younger living donor or a better HLA-matched donor.

**TABLE 3.**  
**Impact of monetary payments on willingness to participate in KPD<sup>a</sup>**

	Less willing, %	No change, %	More willing, %
Reimbursement of lost income	1	36	63
Reimbursement of travel expenses for donor and travelling companion <sup>b</sup>	0	28	72
Compensation for pain and suffering	9	72	18
Cash payment, \$5000	23	63	14
Cash payment, \$10,000	21	63	15
Cash payment, \$20,000	23	59	18
Cash payment, \$50,000	22	56	22

<sup>a</sup> Among 81 donors who indicated they would have been willing to participate in KPD.

<sup>b</sup> Donor but not companion travel expenses are currently reimbursed.

respondents. Cash payments between \$5 000 and \$50 000 were associated with no change in willingness to donate among the majority of donors (Table 3). In response to the question of who should decide regarding participation in KPD, 93% of donors responded this should be a joint decision by the donor and the recipient, whereas 26% responded it should be the donor's decision only, and 12% responded that it should be the recipient's decision only (respondents were allowed to choose more than 1 answer).

**Recipient Survey**

Thirty-eight recipients were approached and consented for study participation during routine posttransplant follow-up appointments (response rate, 100%). The characteristics of the recipients who participated in the study are shown in Table 4. Ninety-two percent (35/38) of recipients indicated that they would have participated in KPD had it been offered at the time of their transplantation.

Table 5 shows the association of selected factors with recipient willingness to participate in KPD; recipients were more willing to participate if there was an advantage to the recipient (i.e., younger donor or better HLA match). The majority of recipients were less willing to participate if surgery was delayed for longer than 3 months. Cash payments between \$5000 and \$50,000 were associated with no change in willingness to participate among the majority of recipients.

**TABLE 4.**  
**Recipient characteristics (N=38)**

Age (mean ± SD)	43 ± 12
Relationship to donor	
Relative	21 (55)
Spouse	7 (19)
Friend	6 (16)
Related through marriage	2 (5)
Other	2 (5)
Race	
White	21 (55)
Asian	14 (37)
Other/unknown	3 (8)
Education	
Grade school	0 (0)
High school	11 (28)
Trade school	6 (16)
College/university	20 (53)
Other	0 (0)
Annual household income	
<\$25,000	2 (5)
\$25,000–50,000	11 (29)
> \$50,000	24 (63)
Unknown	1 (3)

N and percentages shown unless otherwise indicated.

In response to the question of who should decide regarding participation in KPD, 35 (92%) of the recipients responded this should be a joint decision of the donor and the recipient.

## DISCUSSION

This survey of previous directed donors and living donor recipients provides several unique insights that may prove useful in expanding the participation of compatible donor and recipient pairs in KPD programs. The finding that the overwhelming majority of donors indicated a willingness to participate in KPD was surprising and in contrast to information in the published literature. The study also found that a benefit to the recipient, such as a younger donor or a better

HLA-matched donor, as well as the support of the recipient, was an important consideration associated with increased donor willingness to participate. In contrast, cash payments were not associated with increased donor willingness to participate in KPD; however, reimbursement for lost wages and for companion travel may increase willingness to participate in KPD. Finally, delays in transplantation beyond 3 months, but possibly even longer than 1 month would likely limit participation in KPD. Of specific relevance to the Canadian national KPD program, the findings suggest that improving the efficiency of the program may be a prerequisite to including compatible donor and recipient pairs in the program. As of December 2013, the Canadian KPD program had facilitated 240 transplants, but only included 1 compatible donor and recipient pair and had an overall average match cycle completion time of 101 days<sup>1</sup> with the mean plus standard deviation of completion times ranging from 103 ± 14 days for exchanges involving a single exchange, 133 ± 11 for closed chains involving more than 2 pairs, and 112 ± 6 days for domino chains.<sup>8</sup> Currently, transporting living donor kidneys between transplant centers is not permitted in Canada, and donors often must travel in the program. Eliminating the requirement for donor travel and advancement of other strategies to improve the efficiency with which proposed chains are completed between transplant centers separated by large geographic differences (ie, use of video-conferencing to expedite transplant center approvals) should be pursued to reduce transplant completion times.

There are a number of potential explanations why our findings differ from those previously reported by Ratner et al and Kranenburg et al.<sup>4,5</sup> The most obvious consideration is that our survey involved previous donors, whereas these studies involved individuals who had not yet donated. The fact that the donor responses in our study were provided anonymously and were consistent among donors who were very unsatisfied with their donation experience suggests our findings are not simply the result of the donors providing socially desirable responses. Nonetheless, we are currently planning to extend these findings in a prospective study of potential directed donors. The participants in the study of Ratner et al<sup>5</sup> were recruited during their first donor

**TABLE 5.**  
**Factors associated with recipient willingness to participated in KPD<sup>a</sup>**

	Less willing, %	No change, %	More willing, %
If there was an advantage to recipient <sup>b</sup>	0	39	61
No advantage to recipient	43	51	6
My donor was enthusiastic about KPD	0	24	76
If participation helped more than 1 other person (length of chain)	11	39	50
If existing relationship with other recipient(s)	10	61	29
If my donor was required to travel out of province	19	76	5
Delay in surgery of < 1 month	5	76	19
Delay in surgery of 1–3 months	5	89	6
Delay in surgery of 3–6 months	33	67	0
Cash payment, \$5000	31	53	16
Cash payment, \$10,000	29	54	17
Cash payment, \$20,000	29	50	21
Cash payment, \$50,000	35	50	15

<sup>a</sup> Among 81 donors who indicated they would have been willing to participate in KPD.

<sup>b</sup> Examples included a younger living donor or a better HLA-matched donor.



evaluation and had not yet been approved for living donation. It is therefore possible that the ambivalence reported in that study was, in part, the result of general uncertainty or uneasiness about living organ donation among participants who were still at an early stage in their evaluation. In the study of Kranenburg et al,<sup>4</sup> all participants were approved for donation. The survey was conducted in person, and the 24 directed donors who participated in the study had KPD explained to them immediately before being surveyed. Although only 6 of 24 directed donors indicated a willingness (answered Yes or probably Yes) to participate in KPD, only 5 definitely ruled out participation, and 13 of 24 were uncertain (answered Unsure or Probably No) about KPD participation. Therefore, part of the ambivalence reported in that study may be related to the short time that respondents had to contemplate their responses. It is also notable that these studies were conducted in 2005 to 2006, when familiarity with KPD was much lower.

The finding that cash payments did not increase donor willingness to participate in KPD suggests that financial incentives may be unnecessary and may even deter directed donors from considering participating in KPD. For example, some donors spontaneously provided comments in the margins of returned surveys, such as, “No reward wanted, this is the gift of life, happy to help,” and “Not comfortable with this idea. I am not selling a kidney.” These findings may have greater implications for the use of incentives to increase live organ donation in general. To date, much of the literature related to incentives has been focused on unrelated individuals who have no personal interest in donating to the recipient. With the relative absence of other motivators, such individuals would likely require large payments to pursue donation. Such inducements would be illegal in most countries including the United States and Canada. In contrast, individuals with some connection to the recipient may be encouraged to donate or multiply the impact of their directed donation by participating in KPD with relatively modest inducements that may be legally and ethically acceptable. To date, payments to directed donors have been limited to reimbursements,<sup>9</sup> and few studies have examined the limits of what would be permissible under existing legislation.<sup>10</sup> In our study, previous donors indicated that full reimbursement of lost wages or payment of companion travel expenses would increase willingness to participate in KPD. In Canada, the average loss in pay related to living donation is over \$2 000.<sup>11</sup> It may be much easier to implement these changes than a fully regulated system of organ donation,<sup>12</sup> and the use of limited incentives might provide needed empirical evidence regarding the impact of incentives on organ donation.

The finding that compatible donors and their recipients may be more willing to participate in KPD in exchange for a better kidney highlights the need for education and transparency in order to ensure compatible donors and recipients are adequately informed before engaging in KPD. For instance, 27% of donors and 49% of recipients were more willing to participate in KPD if the recipient received a kidney from a younger donor. This suggests that there is a significant knowledge gap in the understanding of the impact of donor age on living donor transplant outcomes because living donor age has been shown to have a lower impact on post transplant outcomes than deceased donor age.<sup>13</sup> With the exception of recipients aged 18 to 39 years who appear

to have the best outcomes when transplanted with living donors aged 18 to 39 years, living donor age between 18 and 64 years has been shown to have a minimal impact on allograft half-life.<sup>13</sup> In addition, providing a “better kidney” through a better HLA match might have limited actual impact on long-term transplant survival, and it would be important not to overstate these potential benefits. Therefore, educating prospective compatible donor and recipient pairs on these issues would be critical in order to manage their expectations and ensure informed consent.

Our findings support the concept that providing a benefit to recipients with a compatible living donor is likely an important strategy to increase participation in KPD. Additional benefits that might be considered include prioritization of recipients for repeat deceased donor transplantation in the event of transplant failure, avoidance of common HLA mismatches to reduce the risk of sensitization in patients who may need more than 1 transplant and size matching for large recipients with small directed donors. Our findings also suggest that simple strategies such as sharing information about the number of transplants facilitated or even some basic demographic details, such as the age and duration of dialysis treatment of the patients who received transplants, may be sufficient to motivate directed donors who already made a decision to donate, to extend, or multiply their gift by participating in KPD. Further research to understand the types of benefit that would help overcome concerns (i.e., delays in transplantation) related to participation in KPD is needed.

Readers of this study should consider the inherent limitations of this single-center survey study. Canadians are provided with lifelong health insurance coverage, and the majority of participants in our study were of white race, and thus the findings may not be applicable to other regions or countries. It is possible that donors who are responsible for their own health care costs may have responded differently to participants in this study. Because the surveys were anonymous, we are not able to link donor and recipient responses. Nonresponse bias, social desirability bias, and recall bias (donors were asked to reflect on events that may have taken place many years prior) are additional considerations. Ethnic minority donors were under-represented among survey respondents; however, the responses of the 17 non-white donors were consistent with the responses of white donors. Also, our finding that even donors, who were dissatisfied with their previous donation experience, were willing to participate in KPD suggests that social desirability may not have been a substantial concern.

In summary, we found that over 90% of previous directed donors and recipients indicated willingness to participate in KPD. Minimizing the burden of KPD participation, by reducing the time to complete match cycles and eliminating the need for donor travel are likely prerequisites to including directed donors and recipients in KPD. Full reimbursement of lost wages and other expenses related to living donation were associated with an increased willingness to participate in KPD but direct cash payments were not.

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