

# The Psychosocial Adjustment of Kidney Recipients in Canada's Kidney Paired Donation Program

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## Abstract

**Introduction:** Kidney paired donation programs have been implemented globally. The involvement of at least 2 donors in these programs might exacerbate recipients' debt of gratitude and guilt, worries about the donor's health, and worries about graft failure documented by previous studies. However, there is an absence of research on the psychosocial implications of kidney paired donation. This study aimed to provide an in-depth examination of recipients' experience of kidney paired donation, with a focus on psychosocial adjustment. **Methods/Approach:** Individual interviews were conducted with 8 recipients who received a transplant through Canada's Kidney Paired Donation program. Data was analyzed using Interpretative Phenomenological Analysis. **Findings:** Four themes emerged: (a) an emotionally charged relationship with the known donor, (b) optimal distance regulation in the relationship with the anonymous donor, (c) kidney paired donation as a series of ups and downs, and (d) multilayered gratitude. **Discussion:** Findings are considered in relation to extant literature. Issues relevant to the transplant community's clinical and research efforts to provide kidney recipients responsive care are discussed.

## Keywords

kidney transplantation, lived experience, interpretative phenomenological analysis, illness, psychosocial aspects, health care

## Introduction

Kidney paired donation (KPD) matches incompatible pairs of donors and transplant candidates based on their medical information.<sup>1</sup> There are 3 types of KPD chains: straightforward swaps (paired exchange), multiple donor-recipient candidate dyads, and those including an anonymous, nondirected donor (NDAD) and a recipient candidate on the waitlist.<sup>1</sup> In the first two, the recipient of 1 donor-recipient dyad receives a kidney from the donor in the dyad with whom they were matched, who remains anonymous. In the third, an NDAD is a person who does not have an intended recipient yet wishes to donate a kidney altruistically to an unknown candidate.<sup>1</sup> The NDAD is paired with a waitlisted recipient, forming a dyad that is then matched with other registered dyads.<sup>1</sup> Medical outcomes in KPD are comparable to those of direct living donation.<sup>2</sup> National-level programs have been established in the United Kingdom, Canada, Australia, the United States, the Netherlands, and countries in Europe.<sup>1</sup> Canada's KPD program was established in 2009 by Canadian Blood Services.<sup>1</sup>

Posttransplantation, kidney recipients face a set of psychosocial challenges including adherence to a medication regimen with intrusive side effects,<sup>3,4</sup> feelings of guilt and indebtedness toward the donor,<sup>5,6</sup> fears about graft rejection,<sup>7,8</sup> and depression.<sup>9</sup> The social context in which the donor-recipient relationship is embedded can also impact recipients' posttransplantation.<sup>10</sup> For example, living donor kidney recipients experience higher levels of guilt and anxiety than deceased donor kidney recipients,

with the donor's sacrifice, perceived risk of having 1 kidney, and physical cost of the donation cited as potential reasons.<sup>11</sup> Moreover, among lung transplant recipients with low compliance to their immunosuppressive medication regimen, either a close fantasized relationship to the deceased donor or emotional distance toward the transplant was reported.<sup>12</sup> Taken together, these qualitative studies point to the clinical relevance of the broader relational context of donation to posttransplantation psychosocial adjustment.

In KPD, recipients enter a relational context embedding themselves, their known donor, and the anonymous donor(s). The involvement of at least 2 donors might exacerbate challenges affecting recipients' psychosocial adjustment, including burden related to debt of gratitude, guilt, and worries about the donor's health and graft failure. Despite this possibility, there is a paucity of research on the psychosocial implications of KPD. To our knowledge, there is one study on the topic involving structured interviews with set response categories investigating whether participants in the Dutch kidney exchange donation program need additional psychosocial support.<sup>13</sup> Though differences in support needs were not found,<sup>13</sup> additional research

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is needed to draw more certain conclusions. The objective of this study was to gain an in-depth understanding of recipients' lived experience in KPD with a focus on aspects impacting psychosocial adjustment.

## Methods

The design of the study was informed by interpretative phenomenological analysis, a qualitative approach, and we adhered to the Consolidated Criteria for Reporting Qualitative Studies.<sup>14</sup> Using semi-structured interviews on a small sample size, we conducted a detailed analysis of each individual case exploring the most significant aspects of participants' subjective experience and meanings attributed to them. The study was approved by the ethics review board of the authors' academic institution and collaborating university-affiliated hospital. Participants provided written informed consent.

## Setting

One individual interview of 90- to 120 min was conducted by the first author experienced in counselling psychology and providing psychotherapy with kidney recipients who participated

in KPD. Interviews took place online via Zoom or Skype or in person in a private room at the hospital's transplantation clinic. Participants interviewed online were asked to select a room free of disturbance. The online modality was initially chosen to accommodate participants across Canada and maintained due to the coronavirus disease (COVID-19) pandemic. Participants were excluded if they did not speak English or French sufficiently to partake in an in-depth exchange.

## Sampling

We used purposive sampling to recruit recipients who were at least 18 years old, making sure we selected both women and men, who spoke either English or French, resided in different provinces in Canada, and participated in Canada's KPD program 6 months to 5 years prior. This time bracket was selected to ensure sufficient time had elapsed for postsurgery recovery and adjustment, and to limit retrospective bias. Recruitment was conducted through the Kidney Foundation of Canada's website and social media pages and the hospital's transplant team. Five eligible participants were recruited online, and all completed the study. Eleven eligible participants were identified by the transplant team, sent a recruitment letter, then telephoned by the first author. Three completed the study, 5 did not respond, and 3 initially expressed interest but ceased responding to subsequent contact. The consent form and sociodemographic questionnaire were sent by email or post. Once participants provided written consent and returned the questionnaire, an interview date was set. Interviews were conducted until saturation of data. Eight participants completed the study, concurrent with the sample size recommendation of interpretative phenomenological analysis ranging between 3 and 10 to prioritize depth of analysis over breadth of data.<sup>15</sup>

## Information Collection and Analysis

An interview guide was adhered to flexibly and pilot tested to ensure it offered space for personally meaningful answers. Questions covered global experience with KPD, posttransplantation experience, as well as relationships with the known donor, anonymous donor, and, if applicable, the NDAD. Prompts were used. Interviews were recorded via digital voice recorder and transcribed verbatim. Participants had not previously met the first author. During the initial phone call, they were informed of study's objective and the authors' motivation to contribute to efforts geared at improved patient care.

Identifiers were removed from study materials and participants assigned a pseudonym to protect confidentiality. Reflection and reformulation strategies were used to access and clarify meaning in participants' discourse to ensure credibility. The different recruitment channels, diversity of participants' geographic location, and inclusion of English and French-speaking individuals promote transferability and credibility. To ensure rigor a reflective journal recorded reactions, biases, expectations, and considerations of influence on responses and findings.<sup>16</sup> Journaling was intensified during

**Table 1.** Participants' Sociodemographic Characteristics (N = 8).

Characteristic	N (%)	Mean (SD), range
Age (years)		63.3 (4.96), 58 to 72
Time (months) since transplantation		38.5 (14.51), 23 to 58
Sex		
Female	6 (75%)	
Male	2 (25%)	
Marital status		
Married	6 (75%)	
Divorced or single	2 (25%)	
Dialysis pretransplantation		
Yes	5 (62.5%)	
Kidney paired donation chain type		
Straightforward swap	1 (12.5%)	
Multiple donor–recipient candidate dyads	5 (62.5%)	
Anonymous nondirected donor and recipient candidate on the waitlist	2 (25%)	
Treatment for an episode of acute rejection in the last 12 months		
No	8 (100%)	
Province		
Alberta	1 (12.5%)	
British Columbia	1 (12.5%)	
Ontario	3 (37.5%)	
Quebec	3 (37.5%)	
Work status		
Employed (full-time or part-time)	3 (37.5%)	
Retired or unemployed	5 (62.5%)	

analysis. Other steps include discussions with the second author (a clinical psychologist [PhD] and experienced researcher in kidney transplantation), peer debrief, and checking transcripts against the recording twice to ensure reliability. Materials were not returned to participants.

The first author conducted analyses following the iterative 6-step method of interpretative phenomenological analysis.<sup>15</sup> The first transcript was read several times and initial ideas noted as comments. Comments were transformed into emergent themes capturing the essence of what was found in the text at a higher level of abstraction. Next, some emergent themes were grouped together, while others emerged as superordinate concepts. We placed theme clusters most strongly capturing the participant's discourse in a table. These steps were repeated for each transcript. Theme patterns across transcripts were identified and placed in a final, master table that was reviewed by the second author to ensure it captured and was grounded in participants' own words.

## Results

Six women and 2 men from different provinces participated. One participated in a straightforward swap, 5 in chains with multiple dyads, and 2 in chains involving an NDAD. Of the latter, 1 participant did not have a known donor had been placed in a dyad with the NDAD. Mean age was 63.35 years ( $R = 58-72$ ,  $SD = 4.96$ ). Time since surgery varied from 23 to 58 months ( $M = 38.54$ ,  $SD = 14.51$ ). Additional sociodemographic characteristics are provided in Table 1.

### An Emotionally Charged Relationship With the Known Donor

Out of the 7 participants with a known donor, the majority ( $N = 6$ ) reported experiencing guilt, indebtedness and worries about them. These emotions seemed inextricably linked to their sense of accountability for the known donor's well-being. Let us examine an extract from B:

We're very, we're always anxious to know about his health – making sure that he isn't unintentionally starting to have health problems because he only has one kidney. There's always the, um, not really worry... But you sort of say gee, I hope he doesn't face any health issues because of this.

B is describing her fear that the known donor's gesture will compromise his health, displaying a readiness to attribute a decline in his health to the donation. The phrase "because of this" implies causality, pointing to her underlying belief that, should a health issue emerge, the donation itself and ultimately, she would lie at the root of it. She does not consciously frame such thoughts as worries, negating the term itself: "not really worry." However, repetition of the word "always," such as in the phrase "always anxious," suggests that she is preoccupied by this idea and feelings of guilt arising from it.

There were echoes of B's apprehension in other accounts, but differences emerged regarding the type of well-being for which participants felt responsible. In turn, this determined the subject of their guilt and indebtedness. For example, T felt responsible for her donor's psychological well-being and wanted to repay her by helping her make adaptive decisions in 2 life domains underlying her distress. Accordingly, T's worries were focused on the emotional impact of events related to these domains on her donor.

Many ( $N = 6$ ) also expressed an increased connection with the known donor. Participants had difficulty articulating concrete ways in which this bond manifested itself and employed heartfelt, lyrical language to express it: "It [the transplant] has joined us together for the rest of the years we have left to rejoice on this earth." M's description of a lifelong union showcases its powerful emotional charge. For all, gratitude, which is explored in the fourth theme, appeared to contribute to this stronger bond.

### Optimal Distance Regulation in the Relationship With the Anonymous Donor

Participants' accounts pointed to striving for an optimal level of psychological proximity and distance with the anonymous donor from whom their transplant came. We define proximity seeking as any attempt, behavioral or psychological, to create a sense of affinity and familiarity with the anonymous donor. One common proximity seeking strategy was the projection of generally agreeable characteristics and personal values onto the anonymous donor. In doing so, recipients created an image of their donor that was at once likeable and similar to them.

It's the thought of somebody who is like an angel. I never thought that it was somebody who showed up and said, I want to donate. I thought about somebody who was supporting another relative. His generosity and his love for the relative. It's somebody who cares enough about a relative or even about the humanity of other people, that they are at another level.

In T's view, donation in the context of helping a relative is the highest act of benevolence, one that places the donor "at another level," that of "an angel." T had previously expressed strong family values, prioritizing the provision of support and care to family members in her day-to-day life. By creating a narrative in which her donor was guided by love for family, she imbues them with agreeable qualities and elements of her self-image. Most participants also wrote their anonymous donors a thank you letter and sought information about them from the health care team, attempts we interpret as functioning to create a sense of affinity and familiarity, respectively. Furthermore, most ( $N = 5$ ) were convinced they had spotted their anonymous donor in the clinic by overhearing staff conversations they believed pointed them to the individual in question. We conceive of the latter phenomenon as another

psychological attempt serving to create a sense of familiarity with the anonymous donor.

At the same time, attempts to maintain distance from the anonymous donor surfaced:

At the beginning, my focus was on Q giving me a kidney, and that's the way I wanted it to be. And then, over the last couple of years – I would say more honestly in the last year, I have thought, well yeah, it wouldn't have happened though, without all those other people.

K seems to describe having unwittingly eschewed thoughts of the anonymous donor and other chain members out of the preference to see Q as her direct donor. A psychological development unfolded over years, culminating in the integration of the anonymous donor and chain members in her transplantation experience. This evolution occurred outside her conscious awareness, with the involvement of others eventually emerging as a spontaneous realization.

Simultaneously, K was convinced she had identified her anonymous donor after overhearing a conversation at the clinic. Thus, attempts aimed at achieving proximity and distance co-existed for K and for others, too. Some expressed the desire to preserve anonymity due to undesirable consequences they could envision, such as requests for financial assistance. Overall, a pattern of proximity seeking balanced against distance maintenance emerged.

## KPD as a Series of Ups and Downs

Participants described their experience with KPD as a succession of gratifying and distressing experiences. While gratifying moments were consistent between participants, notably finding a match and scheduling the transplantation date, events that constituted stressors varied somewhat. Waiting for a match was a common stressor, evoking fear fueled by uncertainty regarding the future, illustrated by N: "My worries were centered around what will happen to me, what will I do? Because of that I was anxious all summer."

Once the transplantation was scheduled, waiting kindled fears of the chain breaking: "It was a very emotional time. Just because - we can be responsible for ourselves, but we don't know these other four people." The unknown members and corresponding lack of control and uncertainty V perceives fueled her distress. M experienced waiting differently:

Knowing that freedom [the transplantation date] was close, my dialysis was easier to go through, I had enthusiasm, I came out of my cocoon a little. Life had been heavy for years... When you know you will be liberated from your problem shortly - in my case, the waiting part was easy.

The upcoming transplant represented freedom M felt certain of acquiring; consequently, waiting was easy. The juxtaposition between M's perceived certainty and V's perceived uncertainty, and corresponding feelings of peace and distress, is a snapshot of differences between participants.

Participants described numerous ways of coping. Most dominant were forming trusting relationships with the medical team and relying on family support. Relationships with other patients, as well as distraction, positive reframing, and downward comparison strategies also surfaced. T mentioned the distinctive strategy of personalizing dialysis equipment and forming friendly relationships with it during the wait-period. Personalizing the kidney was common, too.

## Multilayered Gratitude

Gratitude emerged in all narratives, extending beyond the known donor towards others involved in the transplantation process. It seemed most intensely felt for the known donor followed by the anonymous donor. Gratitude was more muted and less salient for the NDAD, who was described in words connoting distance. Nevertheless, discussing the NDAD evoked admiration for their selfless gesture, illustrated here by W:

But that person - I think about them more as - I don't know if theoretical is the right word, or if academic is the right word, but somewhat at a distance. But also, in terms of their incredible generosity, not doing it for anybody in particular, but just because they wanted to help out people in need.

W begins by explaining how the NDAD feels slightly removed, then pivots to the awe-striking benevolence with which they are characterized in his mind. For N, the only participant who was placed in a dyad with an NDAD, stronger gratitude seemed directed towards the anonymous donor from whom her kidney came. Participants spontaneously articulated appreciation for chain members as integral to their successful outcome, followed by gratitude toward health professionals, other patients, and provincial and national health care systems:

I am grateful for everything that has been offered in the transplantation process, for the opportunities here in Canada, which offers us these operations. But I'm not out of this yet; I still visit the people I was with, and the nurses, the doctors. To me, they are friends.

M's appreciation encompasses the nation, patients, and the medical team, manifesting itself in a sense of friendship that lives on after the transplantation.

## Discussion

The objective of this study was to shed light on recipients' lived experience in KPD with a focus on psychosocial adjustment. Participants described feelings of indebtedness, guilt, and worry towards the known donor, consistent with prior research on recipients of living donation.<sup>5,6,11</sup> An increased bond and sense of intimacy were also reported. Taken together, these results echo those of previous studies describing complex relational dynamics with the donor,<sup>5</sup> and positive and negative changes in the recipient-donor relationship posttransplantation.<sup>17</sup>

To our knowledge this is the first study to examine whether indebtedness, guilt and worries are exacerbated by KPD due to the presence of more than 1 donor. These emotions did emerge for the anonymous donor, though seemingly less intense and salient than for the known donor but did not appear for the NDAD. Results thus support the association between an existing relationship with the donor and higher levels of guilt.<sup>11</sup> We expand on this by suggesting a causal link between recipients' sense of accountability for the donor's well-being and guilt. We hypothesize that this link also works inversely: along with gratitude, sense of responsibility seems to fuel recipients to care for the known donor, assuaging guilty feelings.

Regarding the relationship with the anonymous donor, participants' discourse alluded to a balance of proximity seeking and distance maintenance, pointing to distance regulation. Prior research has reported kidney recipients' preference to maintain a degree of psychological distance from the anonymous donor, manifested in weighing the desire to learn more about them against self-protection,<sup>18</sup> preference not to meet out of fear of adverse consequences,<sup>19</sup> and lung recipients' use of statements incorporating elements of nearness and distance when discussing their deceased donor.<sup>12</sup> Our results were also consistent with a supplement to Muslin's theory of psychological organ internalization claiming recipients create an image of their deceased donors reflecting their self-image.<sup>20,21</sup>

Proximity-seeking might serve to reassure recipients that their donor was both a good person and similar to them. In the same vein, maintaining distance from them (psychological and physical) could protect this image from disillusionment. Preserving a positive image of the donor might assuage fears of contamination and ultimately graft rejection. This notion was congruent with recipients' fears of being influenced by the graft,<sup>22</sup> beliefs about having adopted some of the donor's traits,<sup>23</sup> identification of graft failure as their biggest stressor,<sup>24</sup> and sense of protection from graft rejection when they perceive greater similarity between themselves and the donor.<sup>25</sup> Our study adds to this body of research by tying approach-avoidance movements together into an optimal distance-regulation mechanism that functions to modulate fears of graft failure.

Stressors specific to KPD emerged in participants' discourse, including fears of not finding a match and the chain breaking. Trusting relationships with medical teams and family support were essential for coping, consistent with research demonstrating their impact on recipients' well-being.<sup>26</sup> Gratitude has been identified as a recurrent theme in the transplantation literature along with difficulties in expressing it.<sup>27</sup> In our group, gratitude was also salient and difficult to put into words. Moreover, like a concentric circle pattern, gratitude was most salient and intense for the known donor, followed by the anonymous donor. It then expanded to the broader context encompassing the NDAD, chain members, medical team, province, and nation.

Limitations of the present study include the possibility of selection bias, as individuals with a positive experience and well-functioning transplants might have been more willing to

participate. The possible influence of retrospective bias on responses was another limitation given that interviews took place on average 38.5 months posttransplantation. Interviews were conducted via 2 modalities, online and in person, though differences between both have been reported as modest and a mix deemed effective.<sup>28</sup> In the typical Canadian pool of KPD candidates, recipients' average age is 48 at first match cycle and half are female.<sup>1</sup> By contrast, in our sample average age was 63.35% and 75% were female, which could affect transferability of results. However, interpretative phenomenological analysis aims to provide an in-depth examination of a particular group rather than making general claims, consistent with its idiographic approach.<sup>15</sup>

## Conclusion

To our knowledge, the present study represents the first investigation of recipients' lived experience of KPD. Results underscore the co-existence of inflated responsibility, guilt, worries and indebtedness with gratitude toward known and anonymous donors, and describe optimal proximity-distance regulation in the relationship with the anonymous donor. Variances in the appraisal and impact of KPD-specific stressors and the crucial role of the medical team and family surfaced. Overall, findings contribute to efforts aimed at promoting responsive, attuned care and improving psychological outcomes of KPD recipients. Our results normalized and brought understanding of KPD recipients' reality to health care professionals, showcasing how their experiences, needs, challenges, and largely adaptive responses paralleled those of recipients of direct living donation and deceased donation. At the same time, though it did not emerge as a central theme in our participant group, health care professionals should be prepared for the possibility that recipients will want to meet their anonymous donor or gain information about them. The question of how much proximity and distance with the anonymous donor is desired by the recipient represents a key distinction between KPD and direct living donation. Accordingly, it is important that health care professionals be ready to address this question with recipients in function of the directives of their transplant center.

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