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A Qualitative Study of Kidney Transplant Recipients' Psychosocial Health

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Résumé

La transplantation rénale est le traitement optimal pour les patients souffrant d'insuffisance rénale, mais elle entraîne également des changements dans le bien-être psychosocial des receveurs après la transplantation. Des recherches antérieures soulignent les craintes de rejet du greffon, ainsi que les sentiments de culpabilité, d'endettement et d’inquiétude envers le donneur. De plus, plusieurs études ont démontré des différences dans les expériences psychologiques des receveurs selon le contexte du don. La relation avec le donneur semble être une source sous-jacente à ces différences.

L'objectif de cette thèse était d'explorer l'expérience des receveurs dans différents contextes de don, avec une concentration sur la relation avec le donneur. Dans notre première étude, nous avons exploré l’expérience vécu des receveurs dans le cadre du programme canadien de dons de reins appariés avec l’objectif d’explorer si la présence d'un donneur vivant connu et d'un donneur anonyme aurait un impact sur leur bien-être psychosocial en exacerbant les sentiments de culpabilité, d'endettement et les inquiétudes. Dans notre deuxième étude, nous avons exploré les expériences des receveurs dans le contexte du don décédé et du don vivant, ainsi que par type de donneur. L'objectif de cette deuxième étude était de mieux comprendre la relation avec le donneur décédé et le donneur vivant, ainsi que son impact sur le bien-être psychosocial des receveurs. Nous avons également cherché à identifier les convergences et les différences des expériences relationnelles entre ces contextes pour mettre en lumière des fondements psychologiques communs ou spécifiques à un contexte.

Nous avons choisi une méthodologie de recherche qualitative utilisant des entretiens individuels semistructurés sur un échantillon de 8 participants et 12 participants dans la première et la deuxième étude, respectivement. Les analyses ont été guidées par une analyse phénoménologique interprétative.

Les résultats du premier article montrent que les receveurs construisent une image positive de leur donneur anonyme et recherchent un niveau optimal de proximité et de distance à leur égard. Au niveau de la relation avec le donneur connu, un sentiment d'intimité se développe après la transplantation. De plus, la gratitude coexiste avec la culpabilité et l'endettement dans la relation avec les donneurs connus et anonymes. Enfin, des facteurs de stress spécifiques au programme de don apparié sont apparus. Les résultats normalisent et apportent une meilleure compréhension de la réalité des receveurs de dons appariés aux professionnels de santé en démontrant les points communs avec les receveurs de dons vivants directs et de dons cadavériques. En ce qui concerne notre deuxième article, les résultats ont mis en évidence l'importance du fardeau du don pour les receveurs, et les sentiments de culpabilité et d'endettement correspondants, ainsi qu'un sens aigu de la responsabilité de prendre soin de la greffe pour montrer que le don n'a pas été vain. Des préoccupations liées à l'asymétrie sont également apparues. Les questions pertinentes aux interventions psychologiques ont été discutées, ainsi que des pistes pour les recherches futures. Nous avons conclu en présentant une synthèse de ces résultats mettant en évidence les domaines communs entre les deux études, qui ont éclairé nos suggestions pour des recherches futures ainsi que les implications cliniques.

Mots-clés : transplantation rénale ; don apparié; don vivant; don décédé; aspects psychosociaux; méthodes qualitatives; expérience vécue; analyse phénoménologique interprétative; soins de santé

Abstract

Kidney transplantation is the optimal treatment for patients coping with kidney failure, but it also leads to changes in recipients' psychosocial well-being post-transplantation. Prior research points to kidney recipients' experience of fears of graft rejection, guilt, indebtedness, and worries toward the donor. Moreover, several studies point to differences in recipients' psychological experiences depending on the donation context, and the relationship with the donor seems to be one source underlying these differences.

The aim of this thesis was to conduct a detailed investigation of recipients' experience in different donation contexts, focusing on the relationship with the donor. In our first study, we explored experiences within the context of Canada's kidney paired donation program to determine whether the presence of both a known, living donor and an anonymous donor would impact recipients’ psychosocial well-being by exacerbating feelings of guilt, indebtedness, and worries about the donor(s). In our second study, we explored recipients' experiences in deceased donation and living donation, as well as by donor type. The aim of this second study was to gain a more precise understanding of the nature of the relationship with the deceased donor and the living donor, in addition to donor type in the latter. We also sought to investigate how this relationship impacts recipients' psychosocial well-being and identify convergences and differences between contexts to shed light on common psychological underpinnings or those specific to a donation context.

We chose a qualitative research methodology using one-to-one semi structured interviews on a sample of 8 participants and 12 participants in the first and second study, respectively. Analyses were guided by interpretative phenomenological analysis.

Results in the first article demonstrate that recipients form a positive image of their anonymous donor and seek an optimal level of proximity and distance towards them. In terms of the relationship with the known donor, an increased sense of intimacy is felt. Moreover, gratitude co-existed with guilt and indebtedness in the relationship with known and anonymous donors. Lastly, KPD-specific stressors emerged, with variances in how they were appraised. Results normalize and bring a better understanding of KPD recipients' reality to healthcare professionals by demonstrating points in common with recipients of direct living donation and deceased donation. In terms of our second article, results showcased the salience of the burden of donation to recipients, and corresponding feelings of guilt and indebtedness, as well as a strong sense of responsibility to take care of the transplant to show the donation wasn't in vain. Concerns related to asymmetry also emerged. Issues relevant to psychological interventions and direction for future studies were discussed. We concluded by presenting a synthesis of these findings highlighting common areas between both studies, which informed our suggestions for future research.

Keywords: kidney transplantation; kidney paired donation; living donation; deceased donation; psychosocial aspects; qualitative methods; lived experience; interpretative phenomenological analysis; health care

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To my happy place.

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1. Global Introduction

1.1 Kidney Transplantation

Kidney transplantation is considered the optimal treatment option in terms of medical and psychosocial outcomes for patients coping with kidney failure (Hoffman, 2020). Relative to patients who continue on dialysis, the transplantation literature demonstrates that kidney transplant recipients experience large improvements in health and physical functioning, as well as quality of life (Landreneau et al., 2010; Wyld et al., 2012). Along with the desire to have a better medical outcome and to cease or avoid dialysis, patients base their decision to undergo kidney transplantation on the possibility that their quality of life will improve (Sebille et al., 2016). Kidney transplantation is widely practiced in transplant centers around the world. There are two types of organ donation for the purposes of transplantation: deceased donation and living donation. Deceased kidney donation occurs when a kidney from a recently deceased person is removed, concordant with the donor's wishes and with consent of their family, then transplanted into a recipient whose kidneys are no longer functioning (Toews & Caulfield, 2016). Living kidney donation takes place when a living person donates their kidney to another person, with directed donation being the most common form. In directed donation, the living donor chooses the recipient of their kidney, such as a biological relative, or a person who is not biologically related to them but who they know either through close relationship or mere acquaintance. Compared to deceased donation, living kidney transplantation offers numerous advantages, such as better medical outcomes for the recipient comprising better overall quality and longer survival of the organ transplant. A report from the National Health Service (2015) illustrates that approximately 77% of kidneys from living donors will continue to function 10 years after transplantation, compared to 72% of kidneys from deceased donors. Moreover, living donation is a safe procedure for the donor (Segev et al., 2010) and can function to increase donors' self-esteem (Pascual et al., 2002).

A major problem for patients who are in the stage of kidney failure is the shortage of available kidneys (Kher & Jha, 2020). The need for organs for transplantation exceeds the available quantity (Kher & Jha, 2020) and most patients will not go on to receive a kidney transplant (Hoffman et al., 2020). Moreover, among patients with an eligible donor willing to undergo transplantation, approximately one-third cannot proceed due to blood group ABO incompatibility or recipient candidates' crossmatch positivity against their prospective donor (Delmonico et al., 2004). The Canadian Institute for Health Information (2020) indicates that, in 2019, a total of 1,789 kidneys were transplanted, 3,299 patients were on the waiting list for a kidney, and 72 patients died on the waiting list (Canadian Institute for Health Information, 2020). Wait times can range from a few months to several years, and the waitlist for kidney transplantation is increasing every year (Kher & Jha, 2020). Nearly one in five patients are delisted from the kidney transplant waitlist, with deterioration of health as the most common reason provided (Sokas et al., 2020). Within Canada, Manitoba has the highest rate of living donation, while British Columbia, Ontario, and Quebec have the highest rates of deceased organ donation (Norris, 2020). On comparisons of donor rates at the international level, Canada falls within the top 20 countries for both deceased and living donation (Norris, 2020). Simultaneously, its donation rates fall significantly below those of top-performing countries, such as the United States (Norris, 2020). In 2020, Canada’s living donor rate was 12 donors per million population, and its deceased donor rate was 19.2 donors per million population (Canadian Institute for Health Information, 2021). Its deceased donor rate represents a 12% decrease compared with 2019, likely due to the Covid-19 pandemic, and a 28% increase since 2011 (Canadian Institute for Health Information, 2021). Its living donor rate represents a 21% decrease from 2019, which is also likely due to the Covid-19 pandemic and is the lowest rate in the last 10 years (Canadian Institute for Health Information, 2021).

Kidney paired donation (KPD) represents an innovative solution to the shortage in available organs by circumventing medical incompatibility between recipient-donor candidate dyads. KPD programs operate through a national registry containing medical information about incompatible recipients and their prospective donors across Canada. Based on this information, KPD pairs recipients and donors, creating chains of matching donors and recipients (Canadian Blood Services, 2020). There are three types of KPD chains: a straightforward exchange between two dyads (paired exchange), chains comprising multiple donor-recipient candidate dyads (closed chain), and chains that include an anonymous, non-directed donor (NDAD) and a recipient candidate on the waitlist (domino chain) (Canadian Blood Services, 2020). In the first two, the recipient of one donor-recipient dyad receives a kidney from the donor in the opposite dyad with whom they were matched. In the third, an NDAD donates a kidney anonymously out of their own good will (Canadian Blood Services, 2020). The NDAD is matched with a recipient candidate on the waitlist, forming a pair that is then matched with other registered dyads in a chain (Canadian Blood Services, 2020). To our knowledge, NDADs have been inherent to KPD programs since their implementation. Typically, between 140 and 150 pairs and eight NDADs participate in each match cycle (Canadian Blood Services, 2020). Moreover, of the 664 transplants completed between 2009 and 2018, 393 (59%) have been from domino exchanges that NDADs rendered possible by starting these chains (Canadian Blood Services, 2020). Canadian transplant centers are governed by anonymity rules requiring that the identity of donors and recipients be concealed from all other members of the chain. Minimal information such as a rough estimate of the donor's age group can be revealed to the recipient by the renal team, while all other information is usually concealed, including their gender, geographic location, and profession.

KPD therefore makes it possible for two or more kidneys to be exchanged per match. In doing so, it expands the pool of living donors, enabling more patients to undergo living donor transplantation with its advantages. It also simultaneously reduces the number of patients who would have previously been on deceased donors lists and the time on the waitlist for individuals without a living donor (Malik & Cole, 2014). KPD has been identified as the most rapidly growing channel of living kidney transplantation (Serur et al., 2014), with medical outcomes such as patient and organ transplant survival equal or better than those of directed living donation (Flechner et al., 2018; Leeser et al., 2020). In Canada, KPD was established by the Canadian Blood Services in 2009 and set up to work in collaboration with living donation programs across Canadian provinces (Canadian Blood Services, 2020). It operates by running a match cycle algorithm three times a year. Every time this algorithm is run, medical information on all the recipient-donor dyads and NDADs included in the registry is compared, and opportunities for kidney transplantation are identified (Canadian Blood Services, 2020). As of May 1st, 2019, 664 transplants have been performed through it in Canada alone (Canadian Blood Services, 2020). National-level KPD programs have gained an international presence, including the United Kingdom, Australia, the United States, the Netherlands, and numerous European countries (Canadian Blood Services, 2020).

1.2 Psychosocial Aspects of Kidney Transplantation

Until recently, transplant recipients were an understudied population. In the context of living kidney donation, researchers have typically demonstrated an inclination to study the donor's perspective over that of the recipient (Sajjad et al., 2007; Ummel et al., 2011). In the context of deceased donation, the focus has typically been placed on the deceased donor family's perspective to understand their decision-making process around the agreement to donate their loved one's organ(s) (Miller & Breakwell, 2018). Yet recipients face numerous challenges post-transplantation, which renders this period a challenging one requiring significant adaptation on their part. The preference for donors was fueled by interest in exploring the motivation behind their decision to undergo elective surgery for the benefit of another and whether it comes with a psychological cost, concerns about risks to the donor during surgery and recovery, as well as long-term risks incurred (Pérez-San-Gregorio et al., 2017; Venkat & Eshelman, 2014). In comparison, recipients' decision to undergo transplantation was considered as more straightforward, stemming from a medical need and an opportunity for improved quality of life. Within the last decade, researchers have started to turn their focus on kidney transplant recipients. The literature on the experience on receiving a kidney has expanded, and knowledge on the topic is gradually becoming more finetuned.

It has repeatedly been demonstrated that the process of accepting the donor's offer and acclimating to the post-transplantation period involves far more complexity and nuance than simply obtaining a transplant and experiencing the advantages and improvements that come with it. The medical dimension of life post-transplantation alone requires substantial adjustment. Recipients are immunocompromised because of anti-rejection medications, which increases their vulnerability to infections (Olbrisch et al., 2002). They must also implement changes in numerous health-related domains, including nutrition, exercise, and weight control to optimize their medical outcomes (Laederach-Hoffman & Bunzel, 2000). Furthermore, the psychological health of kidney recipients undergoes a shift, with psychological distress emerging in various forms following transplantation. For instance, considerable fears about graft rejection have been reported (Jones et al., 2020) and Gill (2012) identified these fears as the biggest source of stress for kidney recipients. Other studies have focused exclusively on the prevalence of depression among this population (Palmer et al., 2013; Srifuengfung et al., 2017), with evidence of an association between depression and mortality found (Veater & East, 2016). Clinically significant levels of anxiety, in addition to depression, have also been highlighted by Zimmermann et al., (2016). Taken together, this body of research underscores the fact that recipients must negotiate challenges affecting their psychosocial health across multiple dimensions of their lives. The scope of these challenges renders the post-transplantation period a time of significant adjustment requiring mobilization of their inner resources to cope effectively.

1.3 The Social/ Relational Context as a Key Psychosocial Dimension in Kidney Transplantation

The relational context encompassing the donor and recipient is another facet of the transplantation experience that has psychosocial implications. Recipients seem to be attuned to the particulars of the context surrounding the donation when it comes to their psychological experience of the transplantation. The results of a small body of research comparing transplantation experiences among recipients of living and deceased donation and reporting differences in their psychological reactions support this idea. In their study, Gozdowska et al. (2016) reported that positive psychological effects of transplantation depend on the form of donation, as patients receiving a kidney from a living donor declared a greater sense of happiness. In another study, higher feelings of guilt were reported by recipients of living donation compared to those who had received from a deceased donor, with the physical cost of donation and perceived risk to the donor suggested as a potential explanation (Zimmermann et al., 2016). Ummel & Achille (2016) found that the specific interpersonal and social context within which the donation took place was important in shaping kidney recipients' discourse. Divergences in psychological experiences between transplantation settings could be an indication that recipients are sensitive and react to the specific features of each donation context. In essence, they point to the potential for the distinctive features surrounding the donation to influence their psychosocial well-being and to explain the variances in the nature and extent of psychosocial challenges accompanying transplantation. Research that contributes to existing findings by comparing and contrasting experiences in different transplantation contexts through detailed, in-depth, case-by-case examination would have the potential to provide more detail as to how the relationship influences recipients' psychosocial health. This would be of value given the fact that some prior research has touched on the significance on the context and pointed out differences, but more precision on the impact of the context involved has not yet been brought to light. However, these would hold clinical implications by informing psychological interventions for kidney transplantation recipients and information communicated to them by health care teams.

1.3.1 Relationship with the Living Known Donor

In the domain of living kidney transplantation, research has explored the recipient's psychological experience with regard to their relationship with their donor throughout the transplantation process. One key area is the debt of gratitude toward the donor, which has previously been identified as a central issue for transplant recipients (Sanner, 2003). In line with these findings, Franklin and Crombie (2003) reported that, after the transplantation, one quarter of participants (four out of 16) expressed regret because of the perceived obligation they experienced towards their living, related donor, and two stated the view that, from a psychological point of view, a transplant from a deceased donor may have been a better option. Waterman et al. (2006) investigated the psychological barriers and educational needs of kidney recipient candidates, and highlighted issues related to guilt and indebtedness towards the donor, not wanting to harm the donor or inconvenience them, not wanting to accept a kidney that a family member might need later, and not wanting to disappoint the donor in the case of kidney failure. Moreover, all recipients in Franklin and Crombie's (2003) study considering donation reported anxieties about the risk incurred by the donor. These studies all highlight recipients' vulnerabilities when it comes to the donor by showcasing that the possibility of causing them harm or disappointment, as well as the possibility of an imbalance in the relationship would be psychologically challenging to the point where they would potentially refuse the offer of donation. Recipients therefore demonstrate sensitivity to the donor's well-being and to harmony within the relationship, but simultaneously have accepted the offer of donation. This conflict places them in a difficult position.

Several studies have looked into the relational dynamics that unfold in the donor-recipient relationship throughout the transplantation process. Ralph et al.'s (2017) thematic synthesis of qualitative studies on living kidney donors and/or recipients underscored that donation can strengthen donor-recipient relationships, but can also trigger or exacerbate unresolved angst, tension, jealousy and resentment. Importantly, these can impede both donor and recipient well-being and outcome. In their longitudinal study, Spiers et al. (2016) reported that relational dynamics spontaneously emerged in recipients' narratives as a central topic regarding their experience with the transplantation. The authors made this subject the focus of their analysis, and findings showcased complex challenges in the evolving relationship with the donor. Moreover, they suggested that the experience of receiving a kidney may be different depending on the category of donor in question; whether the donor is a parent, sibling, friend or cousin could impact the transplantation experience in and of itself. They called for studies comparing and contrasting patients receiving kidneys from different types of donors to examine whether convergences and divergences in experiences appear between these groups. Ralph et al. (2019) also conducted a longitudinal study on donor-recipient pairs, focusing on their experiences and expectations of their relationship pre- and post-transplantation, and seemingly responding to Spiers et al.'s (2016) call for research by examining differences by donor type. Divergences were found among dyads according to the type of donor from which their kidney came. For instance, spousal dyads differed from parent-child and sibling pairs in terms of expectations that the transplant would enhance overall quality of life as a couple, and increased tension and arguments before the transplant in the former group. They concluded that while donation can strengthen the relationship for some pairs, it can also trigger unexpected conflict, tension, and disappointment in others, and underscored the need for interventions to address such difficulties.

Taken together, the relationship with the known, living donor has an impact on recipients and is an important area of investigation when it comes to studying recipients' post-transplantation psychosocial adjustment. The donor is an important person in recipients' lives, who they worry about and want to protect, and with whom an amicable relationship seems of considerable significance. As such, given the significance of this person, recipients seem to have a predisposition to be sensitive to and experience distress in the event of discord in the relationship, or in reaction to their perception of not being able to repay them enough. Furthermore, the type of donor in question seems to matter, too: whether the donor is a sister or brother, parent or friend, the backdrop of the donation changes. While each relationship is unique, a donor with a parent status versus a donor with a spouse status might have certain characteristics in common, either mitigating or exacerbating challenges. Thus, in addition to the potential for the broad donation backdrop (deceased, living) to impact the psychosocial aspect of recipients' lives, the more immediate context (type of donor) seems to do so as well. The body of research on the latter is small, and additional studies that analyze recipients' experience of the donor relationship in detail, including differences in relational dynamics and psychological experiences by donation context would contribute to a more finetuned understanding of the ways in which the specific relationship exercises its influence on recipients' psychosocial well-being. Moreover, of this small number of studies, the perspective adopted is donor's view or the dyadic point of view. Research of transplantation experiences emphasizing relational dynamics from the recipients' point of view exclusively has the potential to lead to a more nuanced understanding of their own experiences, and the accompanying psychosocial implications. This is important given their unique and distressing position of needing a kidney, but wanting, above all else, to not bring any harm or risk to their donor, placing them in a delicate position to begin with rife with psychosocial challenges. Thus, a study that addresses all these points would respond to a gap of knowledge in the literature.

1.3.2 Relationship with the Deceased Anonymous Donor

The fantasized relationship with the deceased anonymous donor also seems to hold importance for recipients in the context of deceased donation. This notion has its origins in the theory of psychological organ internalization detailed by Muslin (1971, 1972) after exploring transplant recipients' psychological reactions post-transplantation. This theory posits a gradual internalization of the transplanted organ, describing a shift from its initial perception as a foreign body part to its later perception as a part of one's own body in three stages. In the first stage, the transplanted organ is perceived as an object separate from the self, in the second stage, it is increasingly perceived as a part of one's own body, and in the third, it is completely integrated into the patient's body image. Lefebvre and Crombez (1972) and Lefebvre et al. (1973) expanded on this theory by including a theoretical component pertaining to the fantasized relationship between the recipient and deceased donor. They posited that in the initial stage of the organ internalization process, recipient and donor are fused: the recipient identifies with the anonymous, fantasized donor by unconsciously blending their own self-image with imaginary characteristics of their donor, while the organ is experienced as foreign. The authors hypothesized that this identification serves to ease their acclimatisation of the transplanted organ, rendering it less threatening and more familiar by portraying the donor as such. In the second phase, the donor is simultaneously perceived as part of the self and an external object. In the third stage, when the transplanted organ is internalized, the donor is experienced as external to oneself. In summary, the recipient initially perceives the unknown, fantasized donor as a reflection of their own self-representation. Gradually, the donor moves away from the recipient's self-image and becomes externalized, while the transplant moves in a reverse direction.

Several studies have explored the imagined relationship recipients form with their deceased donor. For instance, in one investigation of lung transplant recipients, a close, fantasized relationship with the deceased donor predicted recipients' chronic stress and psychological distress (Goetzmann et la., 2009). Another study on lung transplant recipients reported that an emotional distance towards the transplanted lung or psychological proximity with the donor contributed to non-compliance towards their immunosuppressive medication regimen (Goetzmann et al., 2007). These studies suggest that forming a close psychological attachment to the donor could compromise recipients' adjustment and outcomes post-transplantation. Furthermore, Neukom et al.'s (2012) qualitative analysis of lung transplant recipients' narratives sheds light on the nature of the relationship with the deceased donor. The authors explained the task recipients face of having to represent the donor in their minds, because they are such an important figure. At the same time, they are also anonymous and inaccessible due to their passing. This makes the task of representing them challenging and accompanied by guilt and separation anxieties (Neukom et al., 2012). The relationship was further characterized as emotionally charged and ambivalent, with joy, connection, separation, alienation, aggression, and guilt, mixed together and tied to one another. In another qualitative investigation, deceased donor recipients' emotional reactions post-transplantation included joy, sorrow, gratefulness and indebtedness, guilt and inequity post-transplantation and perceptions that the transplant transferred the donor's characteristics on to them (Sanner, 2003). The latter fueled avoidance of thoughts about the donor stemming from fear of discovering undesirable information about them. Dicks et al. (2018) conducted a literature review on narratives between deceased donor families and organ recipients, and their results underscored that the importance of relationships formed with the deceased donor is a key feature of their experience.

Taken together, these studies illustrate that the relationship formed with the anonymous deceased donor impacts recipients and continues to do so after the transplantation. Each of these studies points to different aspects of this relationship when describing its impact on the recipient: the proximity to the donor, the difficulty of representing them and coping with the multi-faceted strong emotions they evoke, as well as fears of being influenced by the graft. What they all have in common, however, is the fact that this relationship is experienced as real for the recipient and has a real impact on their psychosocial well-being. This stems from the fact that the deceased donor, like the living donor for recipients of living donation, is a figure who occupies an important role in their lives and whose psychological presence is felt. Yet much remains unknown about this relationship. For instance, whether recipients feel more guilt or indebtedness towards the deceased donor or the donor family, an unconscious sense of responsibility for the donor's death, and how they perceive and define their role in the relationship with the deceased donor are all questions with important clinical implications to which the answer cannot be found in the existing literature to date. Unearthing recipients' fantasized experiences with and representations of the deceased donor with more depth would shed more light on the foundations of this relationship, and pinpoint areas that interventions could assist them in coping and working through the mix of challenging emotions described by prior research.

1.3.3 Relationship with the Living Anonymous Donor and the Living Known Donor in Kidney Paired Donation

KPD represents an original and relatively new channel of transplantation. The types of issues that recipients must cope with, such as the stress that comes with waiting to know if they will be selected or if the donation chain will break are unique to the context. As such, KPD could present recipients with additional psychosocial challenges compared to other forms of kidney transplantation. To our knowledge, only one study has investigated the psychosocial implications of KPD. Kranenberg et al. (2007) presented several factors within KPD that may induce a need for higher levels of psychosocial support, including the decision-making process to participate in exchange programs, the influence of anonymity on participants' wellbeing, limited contact possibilities between dyads post-transplant, and psychological distress in case of not being selected to participate in the exchange program. While the authors found no evidence for additional support needs among recipients of KPD, further research is needed to confirm and extend these findings. Moreover, the authors used a structured interview methodology with predetermined response categories. It is possible that a semi structured interview format could yield different results, as it provides room for participants to bring up personal aspects that researchers may overlook or fail to grasp a priori.

The relational dimension inherent to KPD is also worthy of research attention. To our knowledge, few studies have touched on the relationship with the anonymous donor in paired exchange. Baines et al. (2018) illustrated that recipients constructed an identity of their unknown donor that was familiar and similar to their own by overhearing physicians' conversations in clinic. Furthermore, the greater KPD recipients' perceived similarity with their anonymous donors, the lower their perceived risk of rejection. In an investigation on recipients of living, anonymous donation, Pronk et al. (2016) reported that recipients wished to not know too much information about the anonymous donor’s health.

Through KPD programs, recipients receive a kidney from an anonymous donor, made possible by a kidney donation from a known living donor with whom the recipient has a relationship. Recipients thus enter a relational context that encompasses them, a known donor, and an anonymous donor, rendering this donation climate complex and qualitatively different than that implicated in directed living donation and deceased donation. It is not yet clear whether recipients form a fantasized relationship with the anonymous donor or not, or what the precise nature of the fantasized relationship with the donor is. For instance, it is possible that the anonymous donor is initially perceived in accordance with the recipients' self-representation and eventually externalized, as hypothesized by Lefebvre and Crombez (1972) for recipients of deceased donation. There is also a dearth of knowledge on the impact of the level of closeness with the imagined, anonymous donor on the psychosocial well-being of recipients in KPD programs. Moreover, whether the relationship with the known donor in KPD evolves, and in what way, is not clear. In a similar vein, it is possible that the recipient faces a heavier burden related to his or her debt of gratitude, given that two donors were involved in the donation in KPD. It would be interesting to also examine whether worries for the donor's health and feelings of guilt towards the donor are exacerbated by the fact that two donors were involved in the process. Ultimately, a better understanding of the contextual and relational aspects of transplantation in KPD, and their impact on recipient's psychosocial adjustment must be gained.

1.4 Objective of the Study

The main objective of this thesis was to investigate kidney transplant recipients' experiences of different donation contexts, with an emphasis on the relationship with the donor, and their impact on psychosocial well-being. The two articles comprising this research project shared this overarching aim, but each described experiences within a different donation environment: the first investigated recipients' experiences within KPD, and the second investigated recipients' experiences with deceased and living donation, and across donor type. In doing so, both articles separately addressed areas of the transplantation research literature in which there are gaps in extant knowledge.

In the first study, we aimed to provide an in-depth understanding of recipients' experiences in KPD, with a focus on the fantasized relationship formed with the living, anonymous donor, and the relationship with the known donor. Another objective of this study was to assess whether the context of KPD, including the relationships formed with donors, had an impact on the psychosocial well-being on KPD recipients. The paucity of knowledge on the psychosocial implications of KPD, relational dynamics with the known and anonymous donors in this context, and in particular whether KPD increases the burden of guilt and indebtedness renders our contribution an original one. In doing so, this study will provide much-needed insight into the psychosocial determinants affecting the psychosocial well-being of recipients in this relatively new context of transplantation. Moreover, it will add to the transplantation community's continuing clinical and research efforts to understand the experience of living donation.

In our second study, we investigated the experiences of kidney transplant recipients in different donation contexts, deceased and living, and, within the latter, between different donor types (parents, siblings, friends, etc.). We focused on the relationship with the donor in order to explore whether there are patterns in experiences by context and identify corresponding psychosocial implications for recipients. This topic was chosen because there is a lack of research on the topic even though the select few existing studies in this domain have reported some important psychological differences. This article thus contributes to the existing literature on both deceased and living donation by conducting an in-depth examination of recipients from both contexts, building on existing literature in both areas. In addition, it addresses a gap in knowledge by identifying differences and commonalities according to the context, adding a separate layer of knowledge to the extant literature. Results stemming from this study would also be a source of knowledge for interventions for different types of recipients and contribute to overall improved psychosocial outcomes and satisfaction. This, too, will add to the transplantation community's continuing clinical and research efforts to understand the experience of living donation, as well as deceased donation. Overall, then, this main objective and the sub-objectives comprising it will facilitate the definition of issues that health care teams need to be aware of and address to better prepare, monitor, and support recipients throughout the transplantation process, to ultimately contribute to improved treatment outcomes by facilitating the implementation of strategies promoting their psychosocial adjustment.

The present study is based on an inductive qualitative method and therefore does not posit hypotheses before data collection. There was an expectation that part of the recipients' discourse would be quite similar to and coherent with what has been reported by recipients in prior studies of these contexts. At the same time, we expected that new unique aspects and themes would emerge specific to the context of KPD in the first study. We selected a qualitative research methodology because of its potential to highlight the personal dimensions of transplantation. It was essential to put the focus on recipients' own voices, in their own words, to capture the nuances and specificities inherent to each individual case. Furthermore, interpretative phenomenological analysis (IPA) was selected for the analyses of both articles. This approach attempts to provide rich, detailed examinations of how each person makes sense of major life events. To achieve this aim, this method places its focus on individuals' meaning-making processes inherent to their experience of significant life events rather than on events and their causes (Larkin & Thompson, 2012). IPA has been recommended for health psychology research given the constructed nature underlying the perception of certain aspects of illness (Smith, 1996) and its ability to illuminate complex, sensitive, difficult, ambiguous, and emotionally laden subjects (Smith & Osborn, 2015). To this effect, several studies have been published that involve patient populations and IPA as the chosen method of analysis (Ummel & Achille, 2016).

1.5 Co-Authors' Contributions

For each article presented in this dissertation, the author of this thesis was the main contributor in the steps of the research process, from designing the study to writing the articles. At every step of the research process, Dr. Marie Achille provided supervision and direction, and reviewed and helped synthesize preliminary results, reviewed manuscripts, as well as all other written works.

Article 1: The Psychosocial Adjustment of Kidney Recipients in Canada's Kidney Paired Donation Program

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Abstract

Kidney paired donation programs have been implemented globally. The involvement of at least two 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. Individual interviews were conducted with eight recipients who received a transplant through Canada's Kidney Paired Donation program. Data was analyzed using Interpretative Phenomenological Analysis. 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)* multi-layered gratitude. 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; kidney paired donation; living donor; psychosocial aspects; qualitative methods; lived experience; interpretative phenomenological analysis; health care.

Introduction

Kidney paired donation (KPD) matches incompatible pairs of donors and transplant candidates based on their medical information (Canadian Blood Services, 2020). There are three types of KPD chains: straightforward swaps (paired exchange), multiple donor-recipient candidate dyads, and those including an anonymous, non-directed donor (NDAD) and a recipient candidate on the waitlist (Canadian Blood Services, 2020). In the first two, the recipient of one 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 (Canadian Blood Services, 2020). The NDAD is paired with a waitlisted recipient, forming a dyad that is then matched with other registered dyads (Canadian Blood Services, 2020). Medical outcomes in KPD are comparable to those of direct living donation (Leeser et al., 2020). National-level programs have been established in the United Kingdom, Canada, Australia, the United States, the Netherlands, and countries in Europe (Canadian Blood Services, 2020). Canada's KPD program was established in 2009 by Canadian Blood Services (Canadian Blood Services, 2020).

Post-transplantation, kidney recipients face a set of psychosocial challenges including adherence to a medication regimen with intrusive side effects (Jamieson et al., 2016; Harrison et al., 2017), feelings of guilt and indebtedness toward the donor (Spiers et al., 2016; Ralph et al., 2019), fears about graft rejection (Jones et al., 2020; Hoffman et al., 2020), and depression (Srifuengfung et al., 2017). The social context in which the donor-recipient relationship is embedded can also impact recipients' post-transplantation (Ummel & Achille, 2016). 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 one kidney, and physical cost of the donation cited as potential reasons (Zimmermann et al., 2016). 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 (Goetzmann et al., 2007). Taken together, these qualitative studies point to the clinical relevance of the broader relational context of donation to post-transplantation psychosocial adjustment.

In KPD, recipients enter a relational context embedding themselves, their known donor, and the anonymous donor(s). The involvement of at least two 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 (Kranenburg et al., 2007). Though differences in support needs were not found (Kranenburg et al., 2007), additional research 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. We selected a qualitative approach. In our view, the flexibility afforded by semi-structured interviews is highly relevant for a relatively novel transplantation context on which little is known from the angle of lived experience.

Methods

We chose interpretative phenomenological analysis (IPA) for the analyses. IPA employs semi-structured interviews to investigate how individuals make sense of major life events and capture the most significant aspects of their experience (Smith & Osborn, 2015). IPA also examines the convergence and divergence of experiences within the participant group (Smith & Osborn, 2015). By shedding light on sensitive, multifaceted topics and developing an in-depth view of a phenomenon within a specific context, IPA lends itself well to health psychology research. The study was approved by the ethics review board of the authors' academic institution and collaborating university-affiliated hospital. Participants provided written informed consent.

Study Design

The design of the study was informed by interpretative phenomenological analysis, a qualitative approach devoted to exploring the subjective experience and meaning individuals attribute to particular events, experiences and states (Smith & Osborn, 2015). Using semi-structured interviews on a small sample size, this method enabled us to conduct an in-depth analysis of each individual's lived experience within KPD and to attempt to capture the most significant aspects of their experience. It is based on the philosophies of phenomenology, hermeneutics, and idiography (Smith & Osborn, 2015). Its phenomenological roots underlie its focus on participants' personal experience and perception of a phenomenon (Smith & Osborn, 2015). Moreover, interpretative phenomenological analysis takes the stance that, due to the researcher's own conceptions, complete access into the participant's view can never be achieved. Instead, a two-stage interpretation process, or double hermeneutic, is involved: participants attempt to make sense of their world while the researcher endeavors to make sense of participants' sense-making (Smith & Osborn, 2015). Lastly, we performed a detailed analysis of each individual case, true to the idiographic approach underlying interpretative phenomenological analysis. We adhered to the Consolidated Criteria for Reporting Qualitative Studies (COREQ; Tong et al., 2007).

Participants

One individual interview of 90- to 120- minutes was conducted by the first author (a female PhD student with an MA in counselling psychology and experience providing psychotherapy) with kidney recipients who participated in KPD (8 in total). Interviews took place online via Zoom or Skype ($n = 6$) or in person in a private room at the hospital's transplantation clinic ($n = 2$). 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. Six women and two men from different provinces participated. One participated in a straightforward swap, five in chains with multiple dyads, and two in chains involving an NDAD. Of the latter, one participant did not have a known donor and thus had been placed in a dyad with the NDAD. Mean age was 63.35 years ($R = 58\text{-}72$, $SD = 4.96$). Time since surgery varied from 23 to 58 months ($M = 38.54$, $SD = 14.51$). Additional sociodemographic characteristics are provided in Table 1.

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 post-surgery 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, five did not respond, and three 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 IPA’s recommendation of 3-10, prioritizing depth of analysis over breadth of data (Smith & Osborn, 2015).

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, post-transplantation 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 the first author kept a reflective journal recording her reactions, biases, expectations, and considerations of her influence on responses and findings. Journaling was intensified during 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 IPA's iterative six-step method (Smith & Osborn, 2015). 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

An Emotionally Charged Relationship with the Known Donor

The majority of participants reported experiencing guilt, indebtedness and worries with regard to the known donor. 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 two 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 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 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.

Multi-Layered 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 (Spiers et al., 2016; Ralph et al., 2019; Zimmermann et al., 2016). 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 (Spiers et al., 2016), and positive and negative changes in the recipient-donor relationship post-transplantation (Ralph et al., 2017).

To our knowledge this is the first study to examine whether indebtedness, guilt and worries may be exacerbated by KPD due to the presence of more than one 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 (Zimmermann et al., 2016). 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 (Slaats et al., 2018), preference not to meet out of fear of adverse consequences (Pronk et al., 2017), and lung recipients' "nearness-distance" statements when discussing their deceased donor (Goetzmann et al., 2007). Our results are 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 (Muslin, 1972; Lefebvre et al., 1973).

Proximity-seeking might serve to reassure recipients that their donor is 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 is congruent with recipients’ fears of being influenced by the graft (Bailey et al., 2016), beliefs about having adopted some of the donor's traits (Hennemann et al., 2021), identification of graft failure as their biggest stressor (Gill, 2012), and sense of protection from graft rejection when they perceive greater similarity between themselves and the donor (Baines et al., 2018). Our study adds to this body of research by tying approach-avoidance movements together into an optimal distance-regulation mechanism that may function to modulate fears of graft failure.

KPD-specific stressors included 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 (Pistorio et al., 2019). Gratitude has been identified as a recurrent theme in the transplantation literature along with difficulties in expressing it (Croft & Maddison, 2017). 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 is another limitation given that interviews took place 38.54 months post-transplantation on average. Interviews were conducted via two modalities, online and in person, though differences between both have been reported as modest and a mix deemed effective (Krouwel et al., 2019). Furthermore, in the typical Canadian pool of KPD candidates, recipients' average age is 48 at first match cycle and half are female (Canadian Blood Services, 2020). By contrast, in our sample average age was 63.35 and 75% were female, which could affect transferability of results. However, IPA aims to provide an in-depth examination of a particular group rather than making general claims, consistent with its idiographic approach (Smith & Osborn, 2015).

Conclusion

To our knowledge, the present study represents the first investigation of recipients' lived experience of KPD. Results underscore the co-existence of 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 normalize and bring a better understanding of KPD recipients' reality to health care professionals, showcasing how their experiences, needs, challenges, and largely adaptive responses parallel 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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Table 1. Participants' Sociodemographic Characteristics

Characteristic	*n*	*M* (range), *SD*
Age (years)		63.35 (58-72), 4.96
Time (months) since transplantation		38.54 (23-58), 14.51
Sex		
Female	6	
Male	2	
Marital status		
Married	6	
Divorced	1	
Single	1	
Dialysis pre-transplantation		
Yes	5	
No	3	
KPD chain type		
Straightforward swap	1	
Multiple donor-recipient candidate dyads	5	
Anonymous non-directed donor and recipient candidate on the waitlist	2	
Treatment for an episode of acute rejection in the last 12 months		
Yes	-	
No	8	
Province		
Alberta	1	
British Columbia	1	
Ontario	3	
Quebec	3	
Work status		
Full-time	2	
Part-time	1	
Unemployed	1	
Retired	4	

N = 8.

Article 2: The Psychosocial Adjustment of Kidney Recipients According to Context of Donation

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Abstract

In the context of kidney transplantation, prior research points to the impact of the relationship with the donor on recipients' psychosocial well-being. Psychological differences have been found between recipients of deceased and living donation, and previous studies also report that the experience of transplantation in directed living donation could differ considerably depending on the type of donor from whom the recipient receives (e.g., sibling, parent, friend, etc.). The relationship with the donor seems to be one factor underlying these differences. Yet much remains unclear regarding commonalities and divergences in relational experiences across contexts, and more precise mechanisms through which the donor relationship impacts recipients. The objective of the present study was to conduct an in-depth, detailed investigation of kidney recipients' experiences within deceased and living donation contexts, and, in the latter, by donor type. Individual interviews were conducted with twelve kidney transplant recipients. Data was analyzed using Interpretative Phenomenological Analysis. Three themes emerged: *(a)* salience of and sensitivity toward sacrifice and loss, *(b)* honoring the sacrifice by honoring the gift, and *(c)* relational asymmetry mirroring perceived burden of donation. Findings were contextualized within existing literature on living and deceased kidney donation investigating recipients' experience of transplantation, the impact of regulations on anonymity, and the vital role of information and support from the health care system. Our findings also inform ideas for interventions promoting recipients' psychosocial well-being post-transplantation by underscoring the importance of open communication with recipients, the relevance of addressing themes touching on excessive sense of responsibility, indebtedness, and guilt, and echo prior studies' recommendations that psychological services be made accessible to this population. We conclude with the recommendation that health care professionals and regulations governing transplant centers give serious consideration to recipients’ need for more information or for a meeting with the deceased donor family, while balancing this against considerations of recipients’ vulnerability to being influenced by the donor family's wishes.

Keywords: kidney transplantation; deceased donation; living donation; donor relationship; deceased donor; living donor; psychosocial aspects; qualitative methods; lived experience; interpretative phenomenological analysis; health care.

Introduction

End-stage kidney disease (ESKD), the last stage of chronic kidney disease, occurs when kidneys no longer function on their own (Canadian Agency for Drugs and Technologies in Health, 2020). At this stage, kidney transplantation is considered the treatment of choice because it is associated with reduced mortality and morbidity, and superior health-related quality of life (Hoffman et al., 2020). However, it comes with its own challenges for recipients, including lifelong adherence to a complex immunosuppressive regimen (Hoffman et al., 2020) with accompanying adverse side effects (Harrison et al., 2017).

Kidney transplantation leads to changes in the psychosocial dimension of recipients' lives in part through the relationship with the donor. In a thematic synthesis of qualitative studies on living kidney recipients and donors, Ralph et al. (2017) described that donation can trigger or exacerbate unresolved angst, tension, jealousy, and resentment in the donor-recipient relationship, which in turn can impede donor and recipient well-being and outcome. It bears mentioning that most of these studies were conducted from the donor's perspective. In their longitudinal study, Spiers et al. (2016) explored the experiences of living kidney transplant recipients throughout the transplantation process. The relationship with the donor emerged as a central topic in participants' discourse, and results showcased emergent challenges in the donor relationship post-transplantation. The authors furthermore suggested that the experience of receiving a kidney itself may actually differ by donor type (parent, sibling, friend, cousin, etc.), calling for studies examining convergences and divergences between them. To our knowledge, a study by Ralph et al. (2019) is the only one to have done so. The authors compared the transplantation experiences of living kidney donor-recipient dyads and found differences according to category of donor, such as increased conflict among spousal dyads compared to sibling dyads. Overall, while donation strengthened the relationship for some dyads, it triggered unexpected conflict and disappointment in others.

Broader-level comparisons of living and deceased donation point to particularities in each context regarding the ways through which the donor relationship impacts recipients' well-being as well. Zimmerman et al.'s (2016) study demonstrated that higher feelings of guilt towards the donor were reported by recipients of living donation than by recipients of deceased donation. The authors suggested that a closer existing relationship with the donor could drive higher levels of guilt in recipients of living donation, as opposed to the distance inherent in the relationship with the anonymous, deceased donor. In their research with lung transplant recipients, Goetzmann et al.'s (2009) multiple regression analysis demonstrated that a close, fantasized relationship to the donor predicted chronic stress, psychological distress, worry about the transplant, and feelings of guilt. In comparison, patients who built an aloof, separate relationship with the donor reported less stress or distress. They concluded that while only a minority of lung recipients were affected by problems with the donor relationship, they are clinically relevant.

Within kidney paired donation programs, it has also been shown that recipients (as well as their known donors) construct a close relationship with the anonymous donor, in the sense of imagining a donor who is similar to them (Baines et al., 2018). Though this similar identity was imaginary, it felt real to them and was a central factor in their decision to participate in the kidney paired donation program. Furthermore, the greater the perceived similarity with the imagined donor, the lower recipients' perceived risk of rejection. The authors suggested that similarity with the donor served to ease the integration of the donor kidney. Thus, even the nature of recipients' fantasized relationship with anonymous, deceased donors in deceased donation and anonymous, living donors in kidney paired donation appears to play a role in their psychological health.

Taken together, this small body of research points to the clinical importance of the relationship recipients form with their donor for their psychosocial well-being through its potential to evoke guilt, worries, distress, fears of graft rejection, conflict, and disappointment. Subtle variances seem to surface in patients' accounts according to donor type, too. There is a fundamental discrepancy between donors and recipients. While both deceased and living donors make the decision to undergo elective surgery, recipients need a kidney to ensure their survival and avoid impaired quality-of-life on dialysis, rendering them dependent on the good will of donors. They can also never repay the generous gesture of donation and must cope with feeling indebted for life, in addition to the demands of managing their transplant on a daily basis. These circumstances place recipients in a psychologically vulnerable role with regard to the donor, and, along with existing research, point to the impact of the donor relationship as an area worthy of further investigation. A clearer description of the psychological experiences that emerge in this relationship and an attempt to pinpoint underlying appraisals and corresponding feelings with more precision would be of value given the weight it holds for participants. In turn, this would help inform interventions geared at improving psychosocial well-being post-transplantation.

The donor-recipient relationship has usually been examined from the donor's point of view and, less commonly from a dyadic perspective involving recipients and donors from the same pair. While all these studies undoubtedly make a valuable contribution to the transplantation literature, research focusing on recipients' point-of-view would illuminate in more depth their perception of their relationship with the donor and its intersection with their own well-being. The objective of the present study was thus to develop a detailed understanding of recipients' psychological experiences with their donors during the transplantation process. We also sought convergences and divergences in experiences between different donor types, and, more broadly, between living and deceased donation contexts. A qualitative research methodology was chosen to facilitate in-depth investigation.

Methods

For our analyses, we chose interpretative phenomenological analysis (IPA), a qualitative approach that allows an investigation of individuals' personal lived experience and their meaning-making processes surrounding major life events, with a focus on experiential aspects most central and salient to them (Smith, 2015). IPA is an idiographic approach, committed to examining each individual case in detail prior to making general claims (Smith & Osborn, 2015). We deemed IPA relevant for the present study's objective to explore each recipient's unique relational experience throughout the transplantation process. IPA also explores how experiences overlap and differ within the group of participants (Smith, 2015), making it appropriate for the comparison of recipients' relational experiences by donor type and donation context (living, deceased). Lastly, IPA's strength in examining complex, ambiguous and emotionally laden topics (Smith & Osborn, 2015) translates to strong applicability for health psychology research. The research ethics board of the authors' academic institution and the affiliated, collaborating hospital approved the study. Each participant gave written informed consent prior to the scheduling of the interview.

Setting

The first author (a female PhD student with an MA in counselling psychology and experience providing psychotherapy) conducted one-on-one interviews of 90 to 120-minute duration. Our group consisted of participants who had received a kidney transplant in the context of a living, directed donation (*n* = 7) or deceased donation (*n* = 5). We intended to conduct interviews online via Zoom, a collaborative, cloud-based videoconferencing service. We selected this online platform to accommodate participants across Canada and, for those located in Quebec, due to restrictions imposed by the coronavirus disease (COVID-19) pandemic. Most interviews ended up being held via Zoom (*n* = 11), but one was transitioned from Zoom to the telephone due to internet connectivity issues. All participants were asked to choose a private, quiet room.

Participants

To participate, individuals had to be at least 18 years old, speak English or French, and have undergone kidney transplantation in Canada a minimum of 6 months and a maximum of 10 years before the time of the interview. The ten-year cap was meant to place a limit on the influence of retrospective bias on participants' narratives, and the lower limit of 6 months was chosen to ensure enough time elapsed for participants' post-transplantation adjustment. Participants transplanted over 10 years prior were excluded. A total of 12 individuals (eight women, four men) participated. At the time of the interview, mean age was 56.85 years (*R* = 38-65, *SD* = 7.54) and time since transplantation ranged from 14 to 91 months (*M* = 49.17, *SD* = 28.06). Seven participants had a living donor: two received from a parent (mother: *n* = 1, father: *n* = 1), three from a sibling (sister: *n* = 2, brother: *n* = 1), one from a cousin, and one from a friend. Five had a deceased donor. Table 2 presents additional sociodemographic characteristics.

Sampling

For recruitment, we collaborated with the transplant team of the hospital affiliated with the authors' academic institution. We also recruited through the website and social media pages of the Kidney Foundation of Canada. We employed a purposive sampling technique, selecting men and women who were at least 18 years old, living in Canada, fluent in English or French, had received a kidney from a living or deceased donor, and who had undergone transplantation in a Canadian transplant center 6 months to 10 years prior.

First, the transplant team provided the authors with a list of recipients who received a kidney transplant in the last 10 years through their hospital. Recipients from diverse cultural backgrounds who were transplanted at different years within the 10-year range were selected and sent a recruitment letter, then telephoned one week later by the first author. Of these, 24 did not respond, four expressed interest but did not respond to following contact, and four completed the study. By means of the Kidney Foundation of Canada website and social media pages, thirteen interested participants contacted the first author. Of these, three were not eligible due to having been transplanted over 10 years prior, two ceased communication after the initial phone call, and eight participated. In total, 12 participants completed the study. Consent forms and sociodemographic questionnaires were delivered by email or post. An interview date was set once participants returned these documents.

Information Collection and Analysis

We developed an interview guide that we pilot tested to verify whether it offered room for personally meaningful answers beyond its scope. Questions spanned experience with the period leading up to transplantation, post-transplantation, and the relationship with the donor (known or anonymous, depending on the donation context) throughout the transplantation process. The first author flexibly adhered to this guide. When needed, prompts were used to facilitate and focus the discussion. A digital voice recorder was used to record interviews. The first author transcribed all interviews verbatim, then verified transcriptions against recordings to promote reliability. Participants had not met the first author prior to the study.

The first author engaged in reflective journaling to manage subjectivity by contemplating and recording her first impressions, assumptions, reactions, and expectations. She also reflected on her potential influence on participants' responses and on her interpretation of findings (Gabriel, 2018). The first author also relied on reflection and reformulation techniques as a way of clarifying and accessing underlying meaning in participants' dialogue. These steps contributed to the rigor of the study. In-depth discussions were held with the second author (a clinical psychologist and psychology professor specialized in organ transplantation). Identifiers were removed from all documents and pseudonyms used to protect confidentiality.

The six stages of IPA guided our analyses (Smith, 2015). As these stages are cyclical rather than linear, the first author returned to previous steps to finetune her interpretation at different points during analysis. The first transcript was read attentively and repeatedly, and initial ideas were noted in the left margin as comments. Some comments became emergent themes, which represented a more abstract level of the same idea. Next, we combed over emergent themes for connections and divergences. Those that overlapped were grouped together into clusters, while those capturing meaning at another, higher level of abstraction became superordinate themes. Afterwards we selected themes that captured the essential, prominent aspects of the participant's discourse and placed them in a table. This process was repeated for the second through the twelfth transcript. Patterns in the themes between all transcripts were then identified and placed into a master table. Results were discussed with the second author, who verified their accuracy and coherence. Three central and related themes emerged.

Results

Salience of and sensitivity toward sacrifice and loss

The passage below illustrates the central thesis of this paper that recipients of deceased and living donation are mindful of the donor's sacrifice, and, exclusively among deceased donation recipients, of the donor family's loss and sacrifice. The salience of sacrifice and loss underlies their thoughts and guides their actions. For instance, in the context of deceased donation, many participants expressed sadness and regret that their lives could continue and be improved because of the death and generosity of their deceased donor. Furthermore, the donor family's decision to abide by the donor's wish to donate, the cost of this decision, and the loss they experienced also surfaced in many accounts, in unique ways for each. Let us examine K's passage:

> It just bothers me that, you know, their dad was taken, you know, especially - At any age is awful, but I remember us as teenagers, you know, like, our dad was there all the time, whether we were in the yard, or taking us places. ... Especially if they were boys, their father is a role model. And I just think of how much the father can help in their upbringing at that time, you know, 'cause high school - I don't know, it just bothered me when I read that. ... Maybe she [the donor's wife] got married, and everything is good. I pray the best for them all the time, but...yeah. (K, recipient of deceased donation)

K had corresponded with her donor's wife through her transplant center. Through this correspondence, K gained information about their children. She voices sorrow for her donor's children's loss, who were adolescents at the time of his death. She imagines how she would have experienced this loss at their age, and it being magnified by the donor being the same sex as his children, thus representing a crucial figure in their development. Her reflection epitomizes projective empathy, which consists of putting oneself in the situation of another and imagining what oneself would feel. In fact, K is so disposed to empathize with the donor family that she appears to carry the suffering she imagines they felt and worries they are still experiencing.

Twice she states being "bothered" by their loss, using past and present tenses, which suggests her disheartenment has not faded over time. She expresses praying for them, then trails off with "but...yeah," an indication that, in juxtaposition with her hopes, doubts about their well-being remain. The main features comprising K's account emerged in other participants' accounts, each with its own nuances. Their sensitivity and compassion were finetuned to the particularities of the donor family's circumstances. For example, if the deceased donor was a young person, participants voiced sorrow for their parents' loss. If the donor had children, compassion for their children's loss surfaced. Several participants also voiced awareness that the family's mourning process was likely delayed because they had to wait for the donor's operation to be completed before they could hold a funeral. Taken together, participants demonstrated the tendency to imagine the scope of the family's loss and sacrifice, to be attuned to the contextual details surrounding the loss, as well as a vulnerability to be concerned about them.

Among a subset of recipients of living donation, the donor's sacrifice was at the forefront of their thoughts as well. The nature of the perceived sacrifice, and accordingly, of their concern, seemed to depend on the donor's circumstances. For instance, the parent donors in our group were of retirement age. Consequently, their recipients appeared to experience inner conflict and guilt rooted in the belief that they forced their parent to donate by virtue of needing a kidney, ultimately depriving them of relaxation at the stage of their life meant for leisure:

> Like I said, she has high blood pressure, my grandfather, her father, died of a heart attack, so like did they really look at her heart really well?... She’s older, she could be scared, she deserves her retirement, we did not give her an easy life (laughs). ... So yeah, for a while I thought like oh, I'll just wait on the [deceased donor] list and I'll just wait my turn, maybe that's what I should do. (M, recipient of live donation)

M describes the worries she experienced in the past surrounding the decision to accept her mother's offer of donation. She lists the factors she interpreted as indicators of the fragility of her mother's health ("she has high blood pressure ... her father died of a heart attack..."), the fear her mother may have felt but not expressed, and her perception of having interrupted her hard-earned retirement. This showcases her focus on the risk her mother would take, and the sacrifice she would make. Overall, M's emotional experience around the decision-making process was riddled with guilt and inner conflict because the cost of the donation to her mother weighed heavily on her, to the point where she considered declining the offer.

The donor's sacrifice was also mentioned by recipients of sibling donors and the one recipient of a cousin donor. However, the most prominent element in their discourse was the ease with which they seemed to integrate the gesture of donation into a broader relational landscape of strong family values. Expressions of guilt or inner conflict over the donor's sacrifice appeared to be largely absent. Let us look at A's excerpt pertaining to her brother's offer to donate to her:

> Like it wasn't a question. It wasn't a question. We spend more time together now since the transplant. ... And - Like it wasn't even - I didn't have to ask [him to donate]. It's just his selflessness, and it's kind of awe-inspiring. ... At the heart of everything, you peel back all life layers and things like that, he's my brother and I'm his sister. And we might not see eye-to-eye on life decisions, and he might not care about my life decisions, but we're still family and you're going to do right by your family.

A was struck by her brother's immediate and unwavering resolve to be her donor. She repeatedly states that he didn't hesitate to offer, without her even having to ask him, suggesting she still experiences admiration and disbelief recounting the story that she felt at the time. She then inscribes the gesture in the backdrop of their strong family values as an action congruent with their familial context. In contrast with M, A's narrative does not reveal apprehension or strong concerns related to the risks and cost undertaken by her brother by virtue of being her donor.

For L, whose donor was a close friend, the perceived risk incurred by her donor was prominent, echoing the accounts of participants with parent donors:

> She saved my life. You don't forget that, right? It's not something that's light. She didn't just give me something expensive, she gave me a part of herself at cost and risk. There's always a risk for her now. She only has one kidney. That is not a light thing. So yeah, she's definitely family. (L, recipient of live donation)

Exposing herself to "cost and risk" shifted her friend's status to that of a family member. L's perception and appreciation for her donor's sacrifice was so strong that it shifted the foundation of their relationship. Taken together, themes of sacrifice, cost and risk were prominent across recipients in both donation contexts, attuned to the particularities of the donor.

Honoring the sacrifice by honoring the gift

Cognizance of the donor's sacrifice and, solely among deceased donation recipients, of the donor family's loss, seemed to incentivize all participants to honor the gift of the kidney. This meant taking care of it so that the donation would not be in vain, illustrated below by C, a recipient of deceased donation:

> And I have started finally last year, which is just before 5 [years] to actually write that thank you letter... Now I think it's probably time that I do thank them for the gift that they have given, or their family member gave. ... Maybe partially because I wanted to be sure that it [the kidney] was going to be stable. I was maybe afraid of the connection and building the connection and then something happening to the kidney. ... Mainly just to be able to say thank you for the 5 years and the potentially more that I would get. And to maybe build the relationship from here [via annual written correspondence] so that they can appreciate the gift that they gave. (C, recipient of deceased donation)

C reveals having waited to accumulate sufficient evidence of the transplant's success before writing the donor family a letter. This wait-period hints at her underlying motive to protect them from learning about kidney failure if it were to occur, presumably because she imagines the donor's sacrifice and its cost to them would have been perceived to have been in vain. Protecting them from such disappointment thus seemed essential to her. In the same vein, C expresses the preference for regular communication with the family "so that they can appreciate the gift that they gave." Here, her incentive is to share the transplant's success, thereby demonstrating that the donor's gesture served a purpose. Taken together, out of sensitivity to their loss, C's reflections, and decision-making around her correspondence with the donor family, whether to stay silent or reach out, seem driven in part by what she believes would most benefit them.

Other participants' accounts also indicated thoughtful reflection regarding the impact of the donation's outcome on the donor family. Let us examine the following passage by H, a recipient of deceased donation:

> I didn't really expect to have an answer. I told myself, maybe this [the letter] will bring back sad feelings for them, but at least they know that it served something. The donation was a success. ... I didn't expect anything in return. No, I did it - Honestly, the letter I wrote was much more for them than for me. ... That's what would stop me from wanting to meet them. If they wanted to, I would do it, but I wouldn't ask because I'm scared of knowing the whole scope of the person's background.

By considering how her letter could awaken their feelings of grief, H also displays sensitivity towards the donor family's well-being. She ultimately wrote to them, guided by the belief that the benefit they stood to gain from learning their gesture was not in vain would override the potential risk. H even explicitly states acting out of the desire to assuage their loss rather than out of her own interests, along with the willingness to subvert her own preference for anonymity and fears of learning undesirable information about the donor by meeting the family should they desire it. Taken together, caring for the donor family by sharing the gift's success emerged in the discourse of many recipients of deceased donation.

As with C and H, E's thoughts revolve around his donor's family's loss, and his decision to write to them was also based on providing them with comfort: "I know that they suffered a horrible loss. And uh... You know, if there's anything – I just wanted to let them know that it was appreciated. I was really kind of hoping I might, in some way, assuage that loss." However, he reported thinking about his deceased donor more often than C and H did. Consequently, he focuses on giving back to his donor, too:

> It comes back to the word that I used, stewardship. I don't own it. It'll always partly be a part of the donor. Part of the donor is in me. And so I don't own it, but I'm the steward of it. ... I'm just taking care of it for the person who unfortunately isn't around to take care of it anymore. ... I just find myself incredibly lucky to have a part of someone else that's keeping me alive. And in a sense, I'm really just taking care of it. And I think that propels me to do a better job of taking care of it. I think that's a pretty high calling.

E views himself as extremely fortunate to be the recipient of his donor's kidney but makes the distinction that it will always belong to his donor as an extension of the latter. E defines his part in this equation as stepping in to be the kidney's guardian. In turn, adopting the role of caring for the kidney "for the person who unfortunately isn't around to take care of it anymore," he alludes to his sense that he is symbolically taking care of his donor. This infuses his actions with positive meaning and purpose revolving around giving back, transcending his own benefit, and experienced as a "higher calling."

N, who received a kidney transplantation from his sister, expressed an overlapping view, but with certain nuances:

> It [the kidney] represents the sacrifice that Chloe made for me. ... I recognize that it's a gift that I received, and you know, the sacrifice she made to give it to me. ... I don't want to go out in public and risk getting sick, and potentially dying and not getting the use of the kidney that was intended when it was given to me. ... So it's definitely a driving factor in the decisions I make around my personal safety in this time.

For N, the kidney transplant represents his donor's sacrifice rather than an extension of the donor, as it did for E. This contrast between N and E emerged for recipients of living versus deceased donation, respectively. Still, we see echoes of E's account regarding the view of oneself as the kidney's guardian to honor the donor's sacrifice rather than being solely for one's own benefit. Thus, caring for the kidney is infused with the same meaning and purpose of giving something back to the donor to honor their sacrifice. Altogether, among recipients of living and deceased donation, the success of the transplant was important in giving meaning to the donor's sacrifice and fueled their caring for it.

Relational asymmetry mirroring perceived burden of donation

Due to the emotional weight carried by the idea of the donor's sacrifice, and the donor family's loss for deceased donation recipients, participants expressed concerns about asymmetry in the imagined relationship with the deceased donor family or in the relationship with the living donor. We use the term relational asymmetry to refer to an imbalance of power in the context of the relationship with the donor. Relational asymmetry emerged as a key concern among participants in our sample, regardless of whether they detected it in their relationship or anticipated and dreaded its occurrence in the future. The prominence of relational asymmetry differed between deceased and living donation contexts, and, in the latter group, by donor type.

Recipients with deceased donors voiced concerns about relational asymmetry that seemed linked to the risk that the donor family would expect them to demonstrate indebtedness towards them, and corresponding feelings of obligation that could arise. For participants in living donation, concerns about relational asymmetry seemed closely intertwined with the degree to which participants perceived the donation to have been a burden to their donor and resulting feelings of indebtedness and guilt.

In the following passage, G shares his views regarding whether he would want to meet his deceased donor's family:

> Then I said to myself suddenly, maybe I would feel indebted. And maybe they would feel that I should be indebted towards them and also on my end, if I had socio-affective problems, I'm not sure what it's called, I could maybe fall in love with them, and want to be part of their family, when in reality that's not at all the mindset I'm in, whatsoever. I appreciate anonymity. ... It's a gesture of pure generosity, right? They gave without expecting anything in return, they don't even know to whom they donated. So, the family could be people who live in the same neighborhood as me, maybe people I've already come across, or spoken to. I don't know. But it remains mysterious, and for me, it's very good like that. When I think about it, I think about it in a positive way, I imagine them and I'm happy me to imagine them without knowing them.

G perceives potential pitfalls inherent to meeting the donor family related to asymmetry stemming from indebtedness, revealed by his view that they could expect him to repay them. He also perceives the risk of developing strong feelings towards the family, which would distort his perception and carry him away from his current, authentic frame of mind. As his reflection unfolds, he voices admiration for the pure altruism underlying anonymous donation and the magical feelings it evokes in him. For these reasons, he concludes with his preference to maintain anonymity. Most participants also perceived anonymity as a protective barrier against unwanted risks relating to asymmetry, in addition to a way of preserving the magic inherent to the gesture of donation. As such, all recipients of deceased donation voiced satisfaction with the status quo of anonymity, apart from K. Below, K describes her strong desire to form a relationship with the donor family to learn more about her donor:

> Yeah I think about - possibly every day, I would say. ... Sometimes, yeah, sometimes I feel they're [the donor] looking over me. Sometimes when - you know, 'cause I've had things happen to me in my life, I sometimes always have thought, was it them that saved me or helped me, or you know whatever that situation was. Are they my protector? ... They've given me this gift, and it's making me, you know, happy and... letting me live my life, and giving me all the emotions that I could ever imagine, because I'm alive. And... I can't see the person that has given it to me. ... It's like I don't know who I'm feeling all this love for. But it's strong. And maybe that's why I feel sometimes that, you know, if the anonymous thing wasn't so strict, like if I had a picture, you know, that I could keep in my purse, then I would know who I'm feeling this strong emotion, all kinds of emotions for. But right now, I'm blind, and I don't know who I'm feeling it for, but I know this person gave me the most amazing gift ever.

In perceiving her donor as her guardian angel, attributing positive outcomes in her life to his benevolent influence, K's attachment to her donor has a different flavor than that of other participants. Her intense desire to know more about him is central to her discourse and would serve to better define the figure for whom she has such strong affection. The perception of risks regarding meeting the donor family, whether related to asymmetry or other, does not emerge.

For both recipients of living donation with parent donors, asymmetry was also felt, detailed here by T:

> It [the donation] modified the relationship temporarily because, for several months, I felt enormously indebted. I didn't know how to react to the gift that was given to me. So I distanced myself a bit. My father felt it, and we had a good discussion where he told me, 'Stop being

> ridiculous, it doesn't matter, it's life. It's not a gift I'm giving you, it's a gift I'm giving myself.' You know? He wanted his son to live. So that changed my point of view. And after that, I felt better, just having spoken about it. But for several months I felt bad to have forced someone to do this for me. ... One way of putting it, is it's like I felt less capable of looking him in the face, as if I wasn't capable of telling him a big enough thank you. ... And to ask him, who had almost never been to the hospital, to undergo surgery, it was something that troubled me, to force someone to do this.

T shares the overwhelming feelings of indebtedness and guilt he experienced post-transplantation, stemming from his perception that he forced his father to donate and of the enormity of the gift. These feelings overpowered him to the point of rendering avoidance of his father, with whom he had always had a close relationship, his only recourse; he states being unable to look him in the eye because he feels he cannot thank him enough. Only once his father confronted him were they able to move forward seemingly because, in reframing the donation as having benefited himself by saving his son, he enabled T's feelings of indebtedness to subside. In turn, relational equilibrium was restored.

M was likewise concerned about the impact of relational asymmetry in her relationship with her donor mother, manifesting itself in a sense of guilt and indebtedness and resulting in self-imposed pressure to be more agreeable and conflicting with her wish to remain genuine with her. However, M's awareness of this risk, coupled with the absence of over-involvement from her mother regarding caring for her kidney were cited as facilitating the preservation of her authenticity in their relationship.

L, whose donor was her close friend, also experienced feelings of indebtedness that threatened to destabilize their relationship:

> I told her [the donor], there is no equality here. She was very clear that she didn't want or need anything. And I know her to be completely authentic, and that was her heart. That was the process, to simply talk about it, not leave it unsaid. ... It wasn't something I could earn, or give enough back, or anything. And so that's what drove me to talk about it, because I knew we needed to, because I didn't want anything to destroy our friendship, and if that was there, that need to pay back, that would have destroyed it. 'Cause it wouldn't have been authentic.

L is explaining, like T and M, how the emergent perceived asymmetry in the relationship with her donor threatened to compromise it. As with T, open communication was the solution to moving forward. In contrast with T, whose father mitigated the asymmetry by explaining the gesture served him, too, L details that she and her donor had to recognize and fully assimilate it into their relationship to move forward. Paradoxically, this asymmetry piece needed to be fully acknowledged and integrated to prevent her feelings of indebtedness from impacting their relationship. Similarities and subtle differences regarding relational challenges and ways of resolving them thus emerged between participants.

Participants with sibling donors did not mention relational asymmetry. The donation appeared to be more easily integrated into the sibling relationship than for other donor types, allowing gratitude, appreciation, and admiration to take center stage:

> If I tell somebody about my transplant, I'm kind of bragging about it. It's like, yeah, I got this, and I got it from my sister, and that's just the kind of family I come from. ... It's just an opportunity to brag a bit about my family and the generosity and kindness. I think about it as, I'm pretty darn lucky that I've got this, and that I've got the family that I've got. ... It represents, for me, some of the family that I have, and the values that my family has.

For R, the transplant holds significance above and beyond her donor; it symbolizes her of her close-knit family and the love they have for one another. Similarly, for other participants who had received from a sibling, gratitude and admiration for the donor were central to their accounts. Indebtedness, guilt, and perception of asymmetry did not surface.

Importantly, V's account was largely unrelated to these three themes. Her kidney's functioning had not yet stabilized, and she had experienced numerous complications post-transplantation. While she expressed strong gratitude for her donor cousin's gesture, most central to her narrative were her attempts to identify patterns in her kidney's performance to determine whether it would eventually stabilize. Her discourse also centered on her frustrations with the medical team's lack of transparent communication with her and her donor. In line with the second theme regarding the donor's sacrifice, she stated being most upset by the negative impact of the team's poor communication on her sibling. V described that her sibling wanted to donate to her and faced great disappointment upon learning that it would not be permitted, exacerbated by the team's lack of transparency and sensitivity in communication. V reported that, due to the disappointment her sibling felt, her distress for her sibling exceeded her own at the time. Overall, her account underscored the challenged she faced regarding the uncertainty of the transplant's outcome and her frustration with the lack of disclosure, empathic communication, and information related to the transplantation.

Discussion

The primary objective of the present study was to explore kidney recipients' psychological experiences regarding the donor relationship. Its secondary objective was to explore similarities and divergences in psychological experiences between deceased and living directed donation contexts and, within the latter, by donor type. While each story was unique, certain patterns surfaced in participants' discourse. As previously suggested, the experience of receiving a kidney from different sources appeared to result in different emotions (Spiers et al., 2016). We identified three main themes: salience of and sensitivity toward sacrifice and loss, honoring the sacrifice by honoring the gift, and relational asymmetry mirroring perceived burden of donation.

The first theme calls attention to the salience of the perceived burden of donation. Participants' narratives often centered on the sacrifice, risk and cost surrounding donation to which the donor and/or the donor family were exposed. Interestingly, perceived risk and cost were nuanced according to the donor's circumstances. Recipients of deceased donation were prone to sadness for the donor's death and to imagining the donor family's loss in detail, consistent with prior research reporting kidney recipients' expression of grief and sadness for the unknown, deceased donor (Baines et al., 2002), worries about them, and thoughts about what happened to them and their family (Jones et al., 2020). This reaction was common in our sample. It can also be interpreted to be linked to the concept of survivors' guilt that is based on the recipient's view that someone had to die for them to live, which has been cited in prior research on kidney transplant recipients (Jones et al., 2020). It is possible that survivor's guilt exacerbates recipients' focus on the burden of donation, which in turn reinforces feelings of survivor's guilt, and so on.

Within the scope of our first theme, differences appeared between recipients of living donation with parent donors and a friend donor, and those who received from sibling donors and a cousin donor. Notably, concerns about sacrifice, risk and cost surrounding the donation emerged in the former group only. Interestingly, the discourse of the latter group was similar to that of a participant who received from her spouse in Spiers et al.'s (2016) study. The authors described that this participant did not show any sign of feeling beholden to him, and that the transplant was easy for both parties. Ralph et al. (2019) hypothesized that, among recipient-donor sibling dyads in in their study, the donor was less present in the recipient's day-to-day life and did not hold a caregiving role; therefore, when compared with spousal and parent-child dyads, sibling pairs seemed to be more analytical in their approach to decision-making regarding donation. In this sense, the distance may mitigate strong emotions, to a degree. At the same time, the authors reported that the sibling pairs were acutely aware of the imbalance in the power dynamics due to the one-way gift, which contradicts our findings.

One possible explanation for the difference between recipients' reactions to parent and friend donors versus sibling and cousin donors is that the similar, relatively young age between recipients and their donors in the latter group, their, biological bond, and comparable family status render the idea of donation more acceptable because of a combination of familial ties and the presence of health. In contrast, recipients may perceive parent donors as more vulnerable to health issues due to their elderly status. Coupled with their shorter life span and their attainment of the retirement phase, these factors could make it particularly difficult for recipients to expose them to any risk. Furthermore, it is possible that recipients with friend donors could adopt the view that, in the absence of a biological relationship, a friend has no duty to donate; consequently, any exposure to risk on their behalf may infuse recipients with a sense of responsibility and a stronger sense to repay, rendering the sacrifice, risk and cost more salient. Additional studies are needed to explore whether similar dynamics emerge in other samples, and the reasons underlying them.

Prior research has presented the donor's sacrifice, physical cost of donation, and perceived ongoing risk as potential factors underlying higher levels of guilt reported by living kidney recipients compared to those of deceased donation (Griva et al., 2002; Zimmermann et al., 2016). Our results provide support for the component of this idea emphasizing the attention participants place on themes of sacrifice, cost, and risk. We also build on it by positing that their salience could exacerbate recipients' sense of indebtedness and guilt, as well as heighten perceived responsibility for caring for the transplant explored in our second theme. In recipients of deceased donation, the drive to share the transplant's success with the donor family and to care for the kidney also seemed driven by the desire to honor the donor and their family's sacrifice, and the donor family's loss. Interactions, both real and hypothetical, were based on communicating information recipients imagined would be comforting to the family. One participant reported being willing to meet the donor family should they request it, despite a preference for anonymity rooted in her fear of knowing too much about her donor. In summary, the propensity to place considerable weight on the donor family’s well-being in decisions around communication with them emerged spontaneously in narratives and constituted a vulnerability we identified among some participants in our sample. For this reason, we support Pronk et al.'s (2016) recommendation that anonymity remain the norm, along with a passive, standardized approach to its removal in which transplant centers keep a record of donors' and recipients' requests to meet the other party and approve the request only when both donor and recipient have independently requested a meeting. A process in which the donor family's preference to meet the recipient would be communicated to them a priori could exacerbate their tendency to conform to the donor family's wishes.

Our conceptualization that honoring the gift in honor is fueled by the desire to honor the sacrifice surrounding the donation partially aligns with previous findings. Pinter et al.'s (2016) thematic synthesis of qualitative research on kidney recipients identified studies in which gratitude and appreciation for the kidney transplantation led to recipients' moral responsibility to maintain and maximize the longevity of the graft, and to look after themselves (Gill, 2012;

Howell et al., 2012). We extend these results by suggesting that, in addition to gratitude and appreciation, salience of the sacrifice fuels caring for the transplant. Furthermore, Achille et al. (2006) reported that participants with perfect adherence to their immunosuppressive medication regimen expressed more intense feelings of indebtedness (but not guilt) than those who were not perfectly adherent. They suggested that indebtedness coexists with gratitude towards the donor or their family and that their inclination to take the best possible care of their graft makes sense given these emotions. Our findings tie in nicely with this idea.

The differing degrees of asymmetry presented in the third theme pertain to differences in concerns related to relational asymmetry, and corresponding feelings of indebtedness and guilt, between participants. While meeting the donor family was not permitted based on regulations around anonymity governing transplant centers across Canada at the time of the interview, the idea of meeting the donor family stirred up concerns about relational asymmetry for most deceased donor recipients. More precisely, they reported the possibility that becoming acquainted with the donor family would expose them to the family's expectations that they feel indebted, alluding to the possibility of feeling coerced to repay the gesture of the donation. The risk of relational asymmetry was a reason given for the preference to maintain anonymity by most participants, and consistent with the results of another study indicating satisfaction with maintenance of anonymity before and after transplantation among the majority of donors and recipients (Pronk et al., 2016). This finding also echoes results from a study conducted by Dobbels et al. (2009) reporting that 70% of 176 liver transplant recipients were either satisfied or very satisfied with anonymity rules because of anxiety about emotional involvement or feeling obliged to do something in return. Furthermore, the authors (Dobbels et al., 2009) stated that recipients expressed preference to maintain anonymity due to feelings of guilt, out of mutual respect, and due to anxiety about causing additional grief to the donor family. In line with this, most participants in our sample perceived magic inherent to the anonymity of donation rooted in the donor family's act of generosity without expectation of repayment, coupled with the wish to preserve this feeling, as reasons to preserve anonymity. Concerns about stirring up the donor family's feelings of grief were also expressed.

In our study, one participant wanted more information about her donor. This need was important to her and persisted through time, a finding congruent with those of Goetzmann et al.'s (2009) revealing a fraction of lung transplant recipients had persistent frequent thoughts about the donor and with results of Neukom et al.'s (2012) analysis of lung transplant recipients calling attention to emotionally charged fantasized relationships with donors. More precisely, the one recipient who was dissatisfied with anonymity in our sample reported longing to feel closer to her deceased donor, such as by carrying a picture of him with her every day or by obtaining more intimate details about him to better define the person towards whom she experiences strong affection. She expressed her view that the choice to meet the donor family should be made by the individuals involved rather than external agents. These points also capture the sentiment of liver transplant recipients reported by Dobbels et al. (2009) who considered contact with donor families to gain more information about the donor, such as their gender, age, origin, and what they looked like, for example by having a picture of them. On this subject, we further agree with Pronk et al.'s (2016) recommendation that transplant professionals take seriously revoking anonymity for the minority of recipients because we perceive that a minority will have the need for additional information about the donor and possibly closure around the donation that do not necessarily fade through time.

For participants of living donation, the degree of relational asymmetry participants perceived or apprehended and related feelings of indebtedness and guilt was related to the risk they perceived the donor had brought upon themselves. Accordingly, recipients of sibling donors and of a cousin donor did not mention asymmetry as an emergent relational issue post-transplantation, but recipients of parent donors and of a friend donor did. Their concerns regarding asymmetry were inextricably tied to self-imposed pressure to show gratitude, replicating recipients' reports from previous studies (Schipper et al., 2013). Participants presented different solutions that helped surpass this obstacle and protect their relationship from the threat of asymmetry, building on prior reports of participants' evolving relationship with their donors, and different ways or working through relational issues (Spiers et al., 2016)

One participant in our sample expressed lingering frustration with the medical team, echoing participants' dissatisfaction with lack of information and support presented by Jones et al., (2020). Importantly, Hennemenn et al. (2021) found a positive association between ongoing preoccupation with events accompanying transplantation and higher anxiety and depression scores. We support the authors' statement that ongoing preoccupation should be taken seriously and addressed adequately. In the same vein, though it did not emerge as a central theme, some participants brought up their view that psychological services be available as an essential component in the care of kidney transplant patients. This too is consistent with prior research (Jones et al., 2020), and highlights the scope of challenges faced by recipients throughout the transplantation process. Although participants in our sample found effective ways of adjusting to life post-transplantation, congruent with previous studies (Schipper et al., 2014), support from the health care system is crucial and has been shown to correlate positively with quality of life (Gozdowska et al., 2016).

This study had some limitations. First, by expanding the outer bracket of time since transplantation to ten years, the potential of retrospective bias to influence responses was greater. This choice was made to recruit more participants via the Kidney Foundation of Canada, a channel that enabled us to communicate with participants across Canada. These participants tended to have a longer time since transplantation; thus, their retrospective bias could have affected results. Moreover, the number of participants in each subgroup of living donation was too low to allow us to draw conclusions about recipients within these subgroups more generally. Additional studies that involve a higher number of participants in each group are necessary to confirm and expand on our findings. The next limitation of the present study lies in our choice to include 12 participants in our sample, surpassing the recommendation of IPA to include up to ten. This upper limit was recommended by the authors to facilitate prioritizing the depth of analysis over breadth of data (Smith & Osborn, 2015). As such, we took extra precaution to ensure that the inclusion of two extra participants did not take away from the depth of our analysis. Finally, the lack of inclusion of recipients from other donor types, such as one's child, spouse, mother-in-law, or father in-law, or from anonymous, living donors prevented us from comparing the experiences of these donation contexts and convergences or divergences with those included in our study. Further exploration of these processes based on individual case studies would advance clinical practice geared towards supporting patients to process and work through their relational experiences following transplantation.

Conclusion

This study sheds light on recipients' psychological experience of the donor relationship and its impact, including variances by donation context (deceased, living) and donor type. Findings underscore salience of the burden of donation and recipients' related sense of responsibility to demonstrate that the donation was not in vain. In the context of deceased donation, this rendered some participants vulnerable to being influenced by the donor family's wishes. The narratives of participants with living donors emphasized perceived asymmetry and accompanying guilt and indebtedness that mirrored perceived burden, with the exception of those who had received from a sibling or a cousin. Anonymity was seen as a way of preventing issues with the deceased donor family related to asymmetry and of preserving the magic inherent in donation. One participant reported being insufficiently informed and supported by healthcare practitioners, causing distress, and seemingly fueling persistent preoccupation with events surrounding the transplantation. Future studies should investigate whether these themes and the associations we have drawn between them emerge in other participant groups, too, and in what circumstances. It would be valuable if they attempted to replicate findings related to the salience of the burden, whether this fuels guilt and indebtedness because of feelings of inflated responsibility, and whether these feelings in turn maintain focus on the burden. Interventions could then be focused on stopping the cycle of this self-reinforcing loop. This would be a relevant topic for recipients of both deceased and living donation. In the latter group, it would also be of value to investigate under which particular circumstances the burden is felt most strongly (e.g., donor type), and solutions that have helped recipients move past it. Altogether, a better understanding of these issues would contribute to the development of a support system informed by common challenges faced by recipients and improve their post-transplant care.

Our findings have implications for clinical work aiming to improve the psychosocial well-being of kidney transplant recipients. We recommend that transplant teams engage in an open dialogue with recipients and, where applicable, with their donors before the transplantation about potential coping strategies to mitigate feelings of responsibility, indebtedness, and guilt.

Moreover, even though most participants reported adaptive ways of coping, the psychological challenges emerging from their discourse emphasizes the need for accessible psychological services as an available option. Key themes of psychological interventions could revolve around guilt, indebtedness, and responsibility, in addition to challenging perceptions around the perceived heavy burden of donation and providing alternative ways to frame the donation. Furthermore, health care professionals and regulations governing transplant centers should take seriously the need for more information or to meet the deceased donor family, and simultaneously maintain awareness of the vulnerability of recipients to being influenced by the donor family's wishes.

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Table 2. Participants' Sociodemographic Characteristics

Characteristic	*n*	*M* (range), *SD*
Age (years)		56.85 (38-65), 7.54
Time (months) since transplantation		49.17 (14-91), 28.06
Sex		
Female	8	
Male	4	
Marital status		
Married or living with partner	8	
In a couple	1	
Divorced	1	
Single	1	
Widowed	1	
Dialysis pre-transplantation		
Yes	8	
No	4	
Context of donation		
Deceased	5	
Living	7	
Type of donor		
Parent	2	
Sibling	3	
Friend	1	
Cousin	1	
Treatment for an episode of acute rejection in the last 12 months		
Yes	-	
No	12	
Province		
Alberta	1	
British Columbia	3	
Saskatchewan	1	
Ontario	3	
Quebec	4	
Work status		
Full-time	7	
Part-time	2	
Unemployed	2	
Retired	1	

N = 12

4. Global Discussion

4.1 Thesis objectives and summary of findings from Article 1 and Article 2

The global objective of this thesis was to examine kidney transplant recipients' experience in different contexts of donation in detail, with a focus on the impact of the relationship with the donor on psychosocial well-being. For each article, we used a qualitative research methodology in the form of semistructured interviews, informed and analyzed by an interpretative phenomenological analysis framework. We presented and described emergent themes stemming from participants' discourse in each study, which appeared to be most salient, meaningful, and significant to them.

The first study investigated recipients' experience within KPD, and in particular the relationship formed with the known living donor and the anonymous living donor. Four central 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)* multi-layered gratitude.

Participants described feelings of guilt and indebtedness towards their known donor, as well as worries about their well-being. At the same time, an increased sense of closeness was reported. These feelings were described when speaking about the anonymous donor, too, but not the NDAD, suggesting that guilt, indebtedness, and worries increase with the degree of closeness in the relationship. Participants also voiced attempts to care for their known donor's well-being wherever they could, which was adjusted to the type of well-being they perceived as compromised. We suggested that feelings of guilt arise from perceptions of oneself as being responsible for a decline in the donor's well-being, and, in turn, taking on a degree of responsibility for the donor's well-being by caring for them served to assuage guilt. This hypothesis of a causal and inverse relationship between guilt and responsibility must be interpreted with caution, as statements of causality are beyond the scope of the cross-sectional design of this study. Additional research is required to draw conclusions on a causal relationship between these components.

Moreover, in the fantasized relationship with the anonymous donor, participants seemed to balance attempts to forge a sense of closeness with them with attempts to keep a degree of psychological distance. Most participants defined their donors in their own self-image, in addition to imbuing them with positive, likeable characteristics, and were also convinced they had seen them in the clinic despite rationally recognizing they could not be certain of it. Therefore, the need to define the donor was strong, as was the need for this portrayal to be both familiar and agreeable. At the same time, the need to maintain a distance co-existed with the former, seemingly because knowing too much could risk destabilizing the image formed. We interpreted these as psychological acts operating at a level somewhat outside consciousness and tied them together into a distance-regulation mechanism whose function is to regulate fears regarding graft rejection by engineering an image of a donor who is non-threatening, familiar, and kind. Most participants were satisfied with anonymity, but one perceived anonymity rules as too strict and expressed longing for more information about her donor. Her need did not fade through time. Stressors specific to KPD also surfaced in narratives, mainly consisting of fears of never finding a match and of the chain breaking. Gratitude was strong, difficult to put into words, and most salient for donors with whom participants were closest (known and direct anonymous donor), then expanded to include the NDAD, chain members, the medical team, and the broader provincial and national contexts. Participants thus included the broader context in their reflections on their transplantation experience. Overall, results in the first article demonstrate that indebtedness, guilt, and worries are present in the context of KPD. While they may also be exacerbated by this context of donation, given that guilt and indebtedness emerged for both known and anonymous donors while being most strongly felt for the known donor, this did not emerge from our data. The modality of this study does not allow for a statement of causality, either. While aspects unique to KPD surfaced in participants’ narratives, their emotional experiences largely seemed to parallel those reported by recipients in directed donation. Additional studies are needed to investigate this research question with the inclusion of a control group.

In the second article, we explored kidney recipients' experience in deceased and living donation contexts, and by donor type, focusing on the impact of the fantasized relationship with the deceased donor or the relationship with the known direct living donor on recipients' psychosocial well-being. We compared narratives of participants from these different contexts to capture commonalities and discrepancies among them, in turn to attempt to define with more precision the psychological underpinnings of the psychosocial impact of relational experiences to build on existing literature. Three themes surfaced from participants' discourse: *(a)* salience of and sensitivity toward sacrifice and loss, *(b)* honoring the sacrifice by honoring the gift, and *(c)* relational asymmetry mirroring the perceived burden of donation.

Participants' narratives showcased the salience of the sacrifice, risk and cost of the donation to the donor and/or the donor family in their minds. Subtle differences surfaced between the contexts of deceased and living donation in the ways in which the sacrifice, risk and cost were perceived and defined. Mainly, recipients of deceased donation expressed sadness that their donor had to die, and sorrow for the donor family's loss. They conceptualized the family's loss in ways that were aligned with what they knew about the donor and demonstrated the tendency to imagine the scope of their loss with detail and to feel compassion and sorrow for them. Among recipients of living donation, the donor's sacrifice was also conceptualized according to the donor's circumstances. Thus, for this theme, differences were found depending on the type of donor in question, with recipients of parent and friend donors expressing more salience of burden than those of sibling and cousin donors. We attributed this finding to the perception of heightened vulnerability of elderly parents, and of a lack of a biological bond in the case of a friend donor, making their choice to take on risk stand out more to their recipients.

The salience of the burden seemed to correspond to levels of guilt expressed, in addition to a heightened sense of responsibility to care for the transplant to demonstrate that the donation was not in vain. The latter transpired as a very important cause for all. Related to this theme, recipients of deceased donation appeared to be guided in their correspondence with the donor family by the motivation to demonstrate that the donation was not in vain because they were taking good care of the transplant, in the hopes that learning this would assuage their loss. One participant expressed being willing to meet the family, should they ever wish to and should it be possible, despite her preference not to do so. Overall, we perceived a vulnerability among recipients to being influenced by the donor family's wishes, fueled by their awareness of their loss and desire to assuage it. Lastly, concerns about relational asymmetry were expressed in different ways according to the context. For recipients of deceased donation, concerns about asymmetry contributed to the perception of risks inherent to meeting the donor family, and, in turn, was one factor that led to satisfaction with anonymity. However, one participant was not content with anonymity because she yearned to know more about her donor in order to better define towards whom her strong affection was being directed. This need did not appear to fade through time. For recipients of living donation, the degree of relational asymmetry perceived or dreaded seemed to correspond to the salience of the risk and to feelings of guilt and indebtedness. Thus, recipients of parent and friend donors were most concerned about the risk incurred by their donors. This emerged as a challenge in resuming a normal relationship with their donors post-transplantation, which were negotiated or coped with in different ways, but still associated with a considerable degree of disruption and distress. One participant's discourse was an exception to these themes; her narrative centered on the functioning of her kidney, which had not stabilized, as well as frustration with interactions with the medical team. Thus, she seemed preoccupied with events surrounding the transplantation.

Lastly, it is important to consider that the number of recipients in each subgroup of donor type was low. As such, our results should be interpreted with caution. Future investigation is required to confirm and expand these findings in order to draw more certain conclusions about similarities and differences between recipients' experiences in each subgroup of living donation.

4.2 Synthesis of results from both articles in relation to extant literature, and what this means for future research

Commonalities and differences that surfaced from results in both studies helped us identify areas that are experienced as challenging for recipients and point to why this is the case, extending related findings from prior research with the specifics gathered from our participant groups. In this discussion, we highlight areas that were problematic for all recipients. We also identify potential mechanisms for recipients' challenging feelings, attempting to go further than describing their experience by suggesting likely appraisals that evoke the associated feelings described.

4.2.1 Examining excessive responsibility, guilt, indebtedness, and asymmetry more closely

First, results support an association between an existing relationship with the donor and the experience of guilt posited by prior research (Zimmermann et al., 2016). In our first study on KPD, participants felt more guilt towards the known donor, followed by the anonymous donor, but not the altruistic donor (NDAD). In our second study, in general, participants experienced more guilt towards the known donor than the deceased donor. This is not to be confused with the idea that recipients of deceased donation experience less guilt towards the deceased donor. When speaking of their deceased donor, guilt was prominent. However, because recipients with a known donor with whom they have a close relationship and must interact regularly, they are confronted with their own feelings of guilt more often. In contrast, recipients of deceased donation can and seem to keep thoughts of the deceased donor and their family away to some degree, which creates an adaptive buffer against the feelings of guilt they evoke.

Results from both studies lend themselves to the idea of a link between feeling responsible and feeling guilty. In the first study, we posited that participants' sense of responsibility for the donor's well-being fueled a sense of guilt; at the same time, feeling responsible for the donor propelled them to care for them and mitigate their feelings of guilt. In the second study, we came to a somewhat different conclusion: we suggested that the salience of the burden fueled participants to care for the transplant. Given that the salience of the burden was accompanied by feelings of guilt, and that this fueled participants to feel a strong sense of responsibility to care for the transplant, the relationship between guilt and responsibility is apparent. We would argue that this is a 'chicken and egg' situation; whether guilty feelings come before a sense of responsibility, or it's the perception of oneself as responsible that fuels guilty feelings, these two have a symbiotic relationship and feed into one another. The literature has previously touched on guilt as an emotion that surfaces commonly among transplant recipients

(De Groot et al., 2012; Schipper et al., 2013; Spiers et al., 2016), as well as a sense of responsibility towards the transplant (Amerena & Wallace, 2009; Buldukoglu et al., 2005) and towards the donor (Bailey et al., 2016; De Groot et al., 2012). We believe the concept of inflated responsibility that has been described in CBT treatments of obsessive-compulsive disorder is applicable here (Rachman, 2003). It seems likely that it goes hand-in-hand with guilt, and fuels corresponding fears and behaviors.

This relationship between guilt and responsibility makes sense given that the definition of guilt itself includes a component of responsibility. It refers to an emotion where an individual feels responsible for an action (or lack of action) perceived as having negative results. The link between responsibility and obsessive-compulsive disorder was identified over three decades ago (Rachman & Hodgson, 1980) and has become a key component of psychological treatments for OCD (Sookman, 2016). Patients with OCD often believe they are responsible for preventing harm from coming to themselves, a loved one or others (Rachman, 1992). This sense of responsibility fuels them into action to prevent a feared outcome from occurring. Even if the level of danger is assessed to be low, a heightened sense of responsibility and the tendency to assign blame internally rather than externally dictates the need to carry out a compulsion. In other words, elevated responsibility leads to attempts to protect other people from the harm signaled by the obsession (Rachman, 2003). Guilt was linked to responsibility in the context of OCD patients, too (Rachman, 1992).

Although we are not in any way suggesting that transplant patients have OCD, the concept of exaggerated responsibility seems applicable to some degree to the experience of transplant patients as well. Recipients' narratives and emotional experiences in our studies suggest that on an unconscious level, they believe that they did something wrong by having someone donate to them. If they received from a living donor, anonymous or known, the act of donation appears to be perceived as wrong because it exposes them to pain related to surgery and to the risk of harm befalling them associated with the surgery, even if this risk is minor. The more vulnerable the donor is perceived to be (e.g., an elderly parent), the higher the perception that they did something wrong, because the risk seems higher to the person due to their frailty. If the donor is not vulnerable but is seen as having no reason to donate (e.g., a friend), even though the frailty component is absent, the fact that the person is exposing themselves to risk without any familial link might also make them feel that they have done something wrong. When it comes to the deceased donor, the fact that they benefited in any way from their death appears to bring with it moral qualms, too. This appraisal may fuel guilt, or feelings of guilt may fuel this appraisal, but the connection between the two seems strong.

In both studies, based on participants' discourse, feelings of indebtedness appeared separate from feelings of guilt, but seemed to overlap with it. This finding is consistent with Gao et al.'s (2020) computational model of indebtedness. These authors developed theoretical models of indebtedness across three separate experiments. Their findings indicated that guilt from burdening the benefactor and obligation to repay the favor comprise indebtedness, as well as motivate reciprocity.

The results of their study can help make sense of our findings. In our second study, the burden of donation was salient to participants. As stated above, the salience of the burden was accompanied by feelings of indebtedness, which were associated with guilt. The authors' conceptualization of guilt involving burdening the benefactor makes sense of our perception that these two elements were inextricably tied together in participants' narratives. Moreover, in their study, feelings of indebtedness comprised of more prominent levels of guilt than obligation emerged when participants knew that their benefactors had acted out of altruistic intentions. Conversely, when participants learned that the benefactor had an expectation of repayment, possessing strategic intentions, participants' indebtedness was comprised of less guilt and higher feelings of obligation. From the outside, this could seem strange, as one might reason that knowing the donor wanted to help without expecting anything in return might ease feelings of guilt. Yet Gao et al. (2020) suggest that this isn't entirely true. This is consistent with results from our second study, in which one participant's feelings of guilt were only resolved when his donor father underscored how the donation benefited him as well by seeing his son return to a healthier state. Reframing the donation in terms of the donor's altruistic intentions may thus not resolve guilt, and alternative ways to promote recipients' well-being must be implemented.

Moreover, their conceptualization can also help shed light on our results pertaining to asymmetry in both studies. In the first, anonymity was seen as protecting participants from a donor who could expect repayment. In the second, most participants voiced concerns about meeting the deceased donor family due to worries that they would expect them to repay or display feelings of indebtedness to them. They hesitated to meet the donor or donor family because they did not want to discover the expectation of repayment. These results are congruent with those of other studies in which recipients reported fear of inequality in the relationship after transplantation (De Groot et al., 2012). Recipients already feel indebted post-transplantation. However, discovering an expectation of repayment could heighten the obligation component of indebtedness, consistent with Gao et al.'s (2020) results. This would make sense given their vulnerability to being influenced and the fact that sense of obligation is defined as having a kind of coercive quality, and an agreement-like quality tied to social interactions such as promises (Tomasello, 2019). Perhaps the optimal option was to maintain the idea that the donor family donated out of altruistic intentions out of fear of feeling restricted due to coercion should they discover strategic intentions instead.

It would also be valuable to examine differences between responsibility and obligation. We use the term responsibility in our results and in this discussion. In our view, being responsible involves a component of obligation, and could involve carrying out an action, but more central to this definition is a sense of personal accountability for something, ascribing the blame to oneself. As such, it is inextricably tied to guilt on an emotional level. This component separates it conceptually from obligation. At an experiential level, though, responsibility and obligation may overlap substantially. Conversely, they may be experienced as separate from the concept of obligation described by Gao et al. (2020) for recipients. A valuable area of investigation would be to derive a clearer sense of recipients' lived experience of these emotions.

The distinction between sense of responsibility and obligation could also be tentatively conceptualized as stemming from an underlying difference in locus of control. Sense of responsibility seems largely motivated by recipients’ resolve to take good care of their transplanted kidney, at once to honor their donor’s sacrifice and optimize its longevity. In contrast, feelings of obligation seem rooted in an external locus of control, in reaction to the notion of expectations of repayment imposed by external agents in the form of the donor or donor family. Self-determination theory (SDT), the research-based theory of motivation (Deci & Ryan, 1985), could shed light on this topic. SDT posits that people have three fundamental psychological needs, namely the need for autonomy, competence, and relatedness (Ryan & Deci, 2000). The theory that individuals thrive in environments in which they experience satisfaction of these three needs, experiencing high levels of vitality and wellness in such contexts. Conversely, the compromise of one or more of these needs is expected to translate to poorer functioning, and lower levels of well-being. Furthermore, SDT conceptualizes human motivation as intrinsic or autonomous when it is based on volition, such as making a choice based on one's preferences or endorsing an action because one finds it enjoyable or meaningful (Ryan, 1995). In contrast, motivation is considered extrinsic or controlled when it is based on being pressured or controlled by external influences, such as meeting deadlines or carrying out an action because it is instrumental to an outcome (Ryan & Deci, 2000). An individual acting from a place of extrinsic or controlled motivation is hypothesized to have their need for autonomy thwarted and, accordingly, to experience lower levels of well-being. In line with this theory, feelings of obligation may be associated with greater levels of distress compared to sense of responsibility and its links to internal motivation.

Numerous studies lend support to the claim that intrinsic motivation is associated with higher levels of well-being and to the association between extrinsic motivation and lower levels of well-being. For example, one study of adult workers demonstrated that, over the weekend, their positive affect and subjective levels of vitality increased, while negative effects and physical symptoms decreased in relation to those reported during weekdays (Ryan et al., 2010). Importantly, the authors reported that these weekend effects were fully mediated by experiences of autonomy and relatedness. Another study (Coutu et al., 2015) demonstrated that, among a sample of employees working for a provincial government agency, psychological distress was associated with several factors including extrinsic motivation. Extending this theory to transplantation, feelings of obligation tied to the notion of expectations of repayment could threaten to compromise recipients' well-being by thwarting the need for autonomy. Conversely, experiencing the responsibility to care for one's kidney as a choice infused with personal meaning could promote well-being by representing a channel for intrinsic motivation, fulfilling one’s need for autonomy. Applying the lens of SDT to transplantation thus has strong potential to explain similarities and differences in the experience of receiving a kidney, as well as corresponding levels of psychosocial well-being.

4.2.2 Maintaining a positive image of the donor and the protective role of anonymity

An important contribution made by our study is that it underscores the significance of the donor who is anonymous and living, as well as anonymous or deceased, replicating results from prior studies pointing to the central role of the donor. In our first study, the direct anonymous donor was more prominent and significant to the recipient's daily experience post-transplantation than the indirect anonymous donor (the NDAD). We hypothesize that this is likely because the direct anonymous donor is the donor from whom participants' transplant was from. Therefore, the need to represent the donor in a non-threatening way takes priority. We agree with prior hypotheses that forming an image of the donor that is similar to their own self-image is important to assimilate the kidney (Baines et al., 2018). We build on these ideas by suggesting that attributing the donor with characteristics that render them a positive, likeable character serves the same purpose. This aligns with a component of Amerena and Wallace's (2009) suggestion, based on participants' experiences, that the most adaptive hosting outcome is to form a positive relationship with the graft. We posit that a positive image of the donor likely translates into a positive relationship with the graft.

In our second study, the deceased donor and the donor family were in recipients' thoughts, with participants revealing their psychological presence in their minds. Yet the preference to not know too much about the deceased donor surfaced and to limit correspondence with the donor family was desired. In the first study, too, there was a desire to maintain some distance from the anonymous living donor, balancing a sense of closeness with distance through what we interpreted as a psychological mechanism involving optimal distance regulation. It appeared that participants created an outline of a benevolent person but wanted to stop there. This finding replicates results from previous research pointing to recipients' desire to be free from interference combined with the desire for at least some knowledge about the donor (Annema et al., 2015) and concerns about having no information about a donor (Bailey et al., 2016). As Neukom et al. (2012) reported in their qualitative analysis of lung recipients, the relationship with the deceased donor - and to this we add the living anonymous donor in KPD - is one that is charged with ambivalence.

Consequently, the preference to keep anonymity in place was voiced by the majority of participants in both studies. This is consistent with reports of recipients from previous research in which anonymity of the donor was seen as a benefit, freeing recipients from obligation of the gift (Bailey et al., 2016). While it is possible that transplant centers may decide to create more flexible rules over time, we believe that this must be carried out with caution. Recipients in our second study were vulnerable to being influenced by the donor family because of a sense of responsibility to assuage their loss, as well as out of compassion for them. Participants voiced being willing to simply go along with the deceased donor family’s wishes to meet or correspond, if it were possible to do so, despite their own stated preference to remain anonymous and limit the information known about the donor. Participants in both studies voiced concerns related to relational asymmetry. We support Pronk et al.'s (2016) suggestion that revoking anonymity should involve a passive approach rather than an active one. In other words, it would be beneficial if transplant centers instilled a system where, only upon participant's actively voicing a desire to meet the other party would the other party's wishes to meet be communicated to them, and vice versa. Otherwise, simply knowing about the other party's wishes could exacerbate participants' inflated sense of responsibility towards the other party and fuel them to agree, despite feeling it is not in their best interests. This could compromise their psychosocial well-being and outcomes post-transplantation. A passive approach to revoking anonymity could prevent adverse outcomes, while preserving the option to meet and relax anonymity rules where applicable.

A minority of participants longed for more proximity with their unknown donors. In study one, one participant expressed strong desire to know more about the living, anonymous donor and in study two, another one voiced the desire to know more about her deceased donor. The passage of time did not seem to ease this longing, and a lingering sense of dissatisfaction appeared to be present in their current experience. In a related vein, in their study on liver recipients, Dobbels et al. (2009) reported that recipients who considered contact with donor families felt the need to know more about the donor, including receiving a picture. Similarly, the authors reported that these recipients felt that the choice to meet or not should be made by the parties concerned rather than an organization, and some believed it would promote their adjustment if they could choose (Dobbels et al., 2009). This finding echoes the sentiment of the two recipients in our study who were dissatisfied with anonymity, and should be given serious consideration by transplant professionals, in conjunction with an awareness of the vulnerability to coercion underscored by narratives.

For the recipients in both our studies who were dissatisfied with the distance they felt from their donor, their discontent seemed to parallel features of anxious attachment, characterized by preoccupation, seeking a high degree of emotional closeness, and worrying about being abandoned or left behind (Hazan & Shaver, 1987). In contrast, most participants described themselves as satisfied with the anonymity in donation in ways that suggested a secure attachment style. We believe that future studies of the relationship with the unknown donor (anonymous and deceased) would benefit from using the lens of attachment theory towards those who feel dissatisfied with anonymity.

Bowlby extended attachment theory to bereavement (Bowlby, 1980). He posited that individuals who chronically expect rejection or loss (anxious attachment) and those who defensively suppress attachment feelings (avoidant attachment) would likely experience greater psychological and physical distress during bereavement than those with a secure attachment style (Bowlby, 1980). Furthermore, Bowlby identified two types of disordered mourning. The first is chronic mourning, defined as an extended period of intense anger, yearning, anxiety and sorrow, depression, and poor functioning with grief being triggered easily (Bowlby, 1980). On the other end of the continuum was prolonged absence of conscious grieving, characterized by denial of distress and continuation of normal activity (Bowlby, 1980). These two styles were linked to anxious and avoidant styles, respectively. Consistent with this theory, in the domain of adult bereavement, attachment behaviors that parallel those observed in infants (Ainsworth et al., 1978) have been reported. For instance, one study (Field and Sundin, 2001) described that avoidant spouses expressed more negative thoughts about their deceased partner 14 months after their passing than anxiously attached spouses. This was conceptualized as a way of maintaining distance from the deceased spouse to suppress attachment feelings. Anxiously attached bereaved spouses reported more positive thoughts about their partners than avoidant attached spouses. The authors claimed that these frequent positive thoughts were indicative of idealization of their partner (Field and Sundin, 2001).

Lastly, Bowlby (1980) hypothesized that securely attached individuals would ultimately gain a sense of self-growth and deep meaning from the experience of loss (Bowlby, 1980). While securely attached individuals were thought to move through phases that have features of anxious or avoidant attachment, they eventually move out of them and learn to balance attachment to their deceased partner with reinvesting in life. This involves coping with and accepting the loss, and ultimately moving back into daily activities of their lives, creating new relationships with others, while simultaneously drawing on positive working models of their spouse (Mikulincer & Shaver, 2007). This bond with the deceased is an integration of the spousal relationship into their new reality (Shaver & Mikulincer, 2014).

The application of attachment theory to bereavement could shed light on themes of attachment and separation. Put simply, attachment bonds serve to provide security in times of threat and need in the context of a relationship characterized by dependence on one's caregiver, themes which are prominent in the donor-recipient relationship. The donor can be conceptualized as a caregiver in the sense that they are providers to the recipient by extension of providing them with life through the transplant. Furthermore, just as attachment styles determine how individuals tolerate separation from attachment figures such as caregivers and bereaved spouses, working models of the donor could also determine how recipients tolerate separation from them, be it through their passing or regulations around anonymity. In line with Bowlby's theory on attachment in the context of bereavement (1980), secure attachment with the donor would likely involve the development of positive working models of the donor. In our view, this would encompass a perception of the donor as a good person. The recipient might also take comfort in thoughts of their donor when they need to, such as when they experience fears of graft failure, just as children seek comfort and safety from their caregivers in times of threat. Put simply, the donor would be a calm presence imbuing the recipient with feelings of protection, comfort, and affection, to be drawn on in times of need. Overall, this would involve carving out a sense of proximity to the donor, balanced with the ability to accept separation from them and resume functioning without thinking of the donor constantly.

In our view, an anxious attachment style in the context of transplantation would involve a persistent desire and preoccupation with achieving closeness the donor and related fears of rejection and abandonment. More specifically, anxiously attached recipients likely feel intense longing to gain information about their donor to achieve a sense of closeness and security. They likely also experience doubts about whether their donor would like and care for them if they knew them as much as they care for their donor. We also expect that anxiously attached recipients experience an ongoing sense of unease about their separation from the donor and experience this on an emotional level as the donor's *departure*. Rumination about the donor could be linked to this attachment bond, as it would serve the function of achieving a felt sense of proximity to them despite the self-defeating nature of this behavior.

An avoidant attachment style applied to the context of transplantation would be characterized by suppression of attachment feelings within the relationship with the donor. In our view, recipients with an avoidant attachment style would place more emphasis on their ability to care for the transplant in order to foster a strong sense of independence and agency around its management. Relational elements would be downplayed. For instance, attempts to separate the notion of the transplant from thoughts of the donor would likely be demonstrated to minimize sense of proximity to the donor. In line with this notion, we expect that those with an avoidant attachment style would deny wanting to achieve closeness with the donor and fully endorse anonymity rules with less nuance than recipients with other attachment styles. They would be incentivized to react to separation from their donor by maximizing levels of distance from them. As is the case for bereaved spouses, for both insecure attachment styles, the relationship with the donor would likely be characterized by less frequent occurrences of positive emotion. These claims are speculations, as they go beyond the scope of this thesis and require investigation to substantiate them.

Psychological interventions for recipients may focus on creating a secure attachment style with the donor. The gestalt therapy empty chair technique could be relevant in helping recipients achieve a sense of closure towards the unknown donor, as well as in processing unresolved grief towards the deceased donor (Field & Horowitz, 1998) given their expressions of grief and sadness towards the latter. It consists of an experiential exercise guided by the therapist consisting of an ongoing, imagined dialogue with the bereaved. The individual alternates between speaking from two different seats: one seat represents the deceased, and the other seat represents their own vantage point, from which they speak as themselves. They also occupy a third seat, representing the position of an observer from which they disclose their perceptions of the interaction. Chair work is regularly used among bereaved spouse populations, because of its ability to create dialogue between the self and the deceased that provokes vulnerability, creates a vivid, spontaneous experience, and, ultimately, has healing effects (Neimeyer, 2012). In our view, this intervention would be highly relevant for recipients and their imagined donors.

Another practice used among bereaved spouses involves letter writing. More specifically, grievers are encouraged to write letters to and from the deceased to reopen contact with them, such as by asking them questions, expressing their thoughts and feelings, and even asking them for advice (Neimeyer, 2012). This written exchange is meant to serve as a way of promoting a relationship, or symbolic bond, with the lost attachment figure. Its necessity tends to fade over time, as the attachment to the deceased partner gradually becomes internalized (Neimeyer, 2012). We perceive both these exercises to be useful for individuals with insecure attachment in different ways. For recipients with avoidant attachment, they could facilitate access of attachment feelings they attempt to suppress and avoid, serving as a safe channel through which such emotions could be expressed. For recipients with anxious attachment, these experiential exercises could be a way which they create a donor that is soothing, loving, and accepting of them**.** Broadly speaking, for both attachment styles, these exercises could be a way of creating positive working models of the donor. In addition, just as with bereaved spouses, they would ultimately promote the dual tasks of holding on to and letting go of their attachment figure (Salmon, 2015).

4.3 Research limitations

The first limitation of this thesis lies in the fact that we asked recipients retrospectively about their experiences post-transplantation. It is possible that participants may not have an accurate representation in the present of their experience with transplantation in the past, including their relationship with their donor. Retrospective bias could have affected results, especially in the second study in which we sought recipients transplanted up to ten years ago to ensure we would have enough participants. Though the longest time participants reported since transplantation was eight years at the time of the interview, this is still a considerably long amount of time, introducing the likelihood of bias. Another limitation is tied to the interpretative nature of the qualitative research methodology chosen. Despite our application of recommended strategies to manage subjectivity and remain grounded in participants' own words when creating themes representing our results, our interpretations are inevitably biased by our training, personal characteristics, and our personal experience.

The third limitation of this thesis lies in our selection of participants, as those with a more positive transplantation experience, in KPD or in directed living or deceased donation alike, may have been more prone to participate. Perhaps recipients with more negative experiences were not interested in participating in either study because recounting their experiences would have made them relive stronger negative emotions. In the same vein, almost all the recipients in both samples had good, pre-existing relationships with their know donors. While these findings cannot be assumed to be representative or generalizable, the aim of IPA studies is to shed light on the perceptions and experience of a particular group over making generalized claims (Smith & Osborn, 2015).

4.4 Conclusion and recommendations for future research

This thesis sheds light on recipients' experience within different donation contexts, including the relatively novel context of KPD, deceased donation, and living donation. It also explored whether type of donor had an impact on experience. We focused on the relationship with the donor in our investigation of these contexts to determine its impact on recipients' psychosocial well-being and ways through which the relationship exercises its influence. Findings from both studies underscore certain central themes, including the close relationship between a heightened awareness of the burden of donation on the donor, corresponding feelings of guilt and indebtedness, and an accompanying strong sense of responsibility to minimize the burden by demonstrating their care for the transplant across these contexts. However, nuances emerged depending on the context in question. Narratives from both articles also highlight the importance of forming a positive image of the deceased and anonymous living donor, with recipients seeking an optimal degree of proximity and distance to help assimilate the transplant. Furthermore, asymmetry surfaced as a concern. Challenges related to asymmetry in the relationship with the living donor emerged in different ways depending on the type of donor. Anonymity seemed to be seen as protection from concerns tied to asymmetry in the relationship with the anonymous living donor in KPD and the deceased donor family. In living donation with known donors, recipients of parent and friend donors experienced the most challenges related to asymmetry, guilt, and indebtedness. Overall, results point to recipients' sensitivity to the context in which the donation takes place.

These findings have clinical implications, and pave pathways for future research. Because recipients with a close donor cannot avoid feelings of asymmetry and corresponding guilt and indebtedness that emerge post-transplantation, helping them navigate this relationship is crucial. Even though participants in our sample found ways to cope with the relational challenges with their known donor, accessible psychological services that address their concerns could reduce needless suffering and distress. Moreover, guilt and excessive responsibility emerged as a potential area for psychological interventions. Helping recipients unearth unconscious appraisals that they have done something wrong by accepting the donation and finding alternative ways to understand the donation, including a re-allocation of responsibility, could help mitigate feelings of self-blame. Furthermore, with regard to anonymity rules, our results point to recipients who desire more information about their donor against the preference for most to maintain anonymity rules and are in support of a conditional and passive approach to revoking anonymity. We have also put forth suggestions for future studies, including addressing appraisals centered on excessive responsibility. These may maintain levels of guilt and indebtedness. We point to attachment theory as another potentially relevant area for future research. More precisely, the recipient's attachment style in their fantasized relationship with the deceased or anonymous donor could be a valuable area of investigation to identify most effective ways to intervene. Therapeutic techniques drawing on emotion-focused and gestalt therapies could also be useful in assisting recipients in these areas, and future research could explore the relevance for the potential of these tools to assist transplant recipients.

Furthermore, along with Spiers et al. (2016), we reiterate the need for additional IPA studies aiming to compare and contrast recipients' transplantation experience according to different contexts of donation. In addition to recruiting participants whose donors are siblings, parents, friends, and other relatives (e.g., cousins, aunts and uncles, and children), we emphasize the relevance of including partners, who represent a significant percentage of non-genetically related living donors (National Kidney Foundation, 2014). Future studies could also compare and contrast the experience of receiving kidneys in living and deceased donation to build on the small existing body of knowledge on the topic. These studies should include a higher number of recipients in each subgroup of donation to allow for more finetuned comparisons between recipients' experience of transplantation by group. We recommend that this aim be balanced against that of preserving IPA's focus on depth, uniqueness, and detail of each individual's lived experience.

We also recommend that future studies investigate the connection between elements described in our themes echoing findings from numerous studies, including guilt and indebtedness (Neukom et al., 2012; Ralph et al., 2019; Waterman et al., 2006), gratitude (Sanner, 2003), sense of responsibility (Gill, 2012; Howell et al., 2012), and fears of rejection (Jones et al., 2020; Hoffman et al., 2020). The transplantation literature points to the relevance of these components in explaining other outcomes such as transplant-related behaviors, with prior research reporting differences with regard to adherence behaviors depending on whether guilt or indebtedness was most prominent (Ummel & Achille, 2016). Understanding how these elements intersect is a valuable research objective, as it would likely add needed depth to the transplant community's understanding of recipients' experience with donation and inform relevant interventions. We have tentatively described potential ways these elements fit together in an attempt to outline their interplay and directionality of such components. For example, we posited a mechanism of distance maintenance in the relationship with the donor, its protective function against potential risks of relational asymmetry associated with indebtedness and put forth the suggestion that it may serve to mitigate fears of rejection. These ideas exceed the scope of our data, however, and require further investigation. Future studies could test out these hypotheses or investigate alternative explanations. In our view, advances in this area holds significant value in informing the promotion of recipients' psychosocial health.

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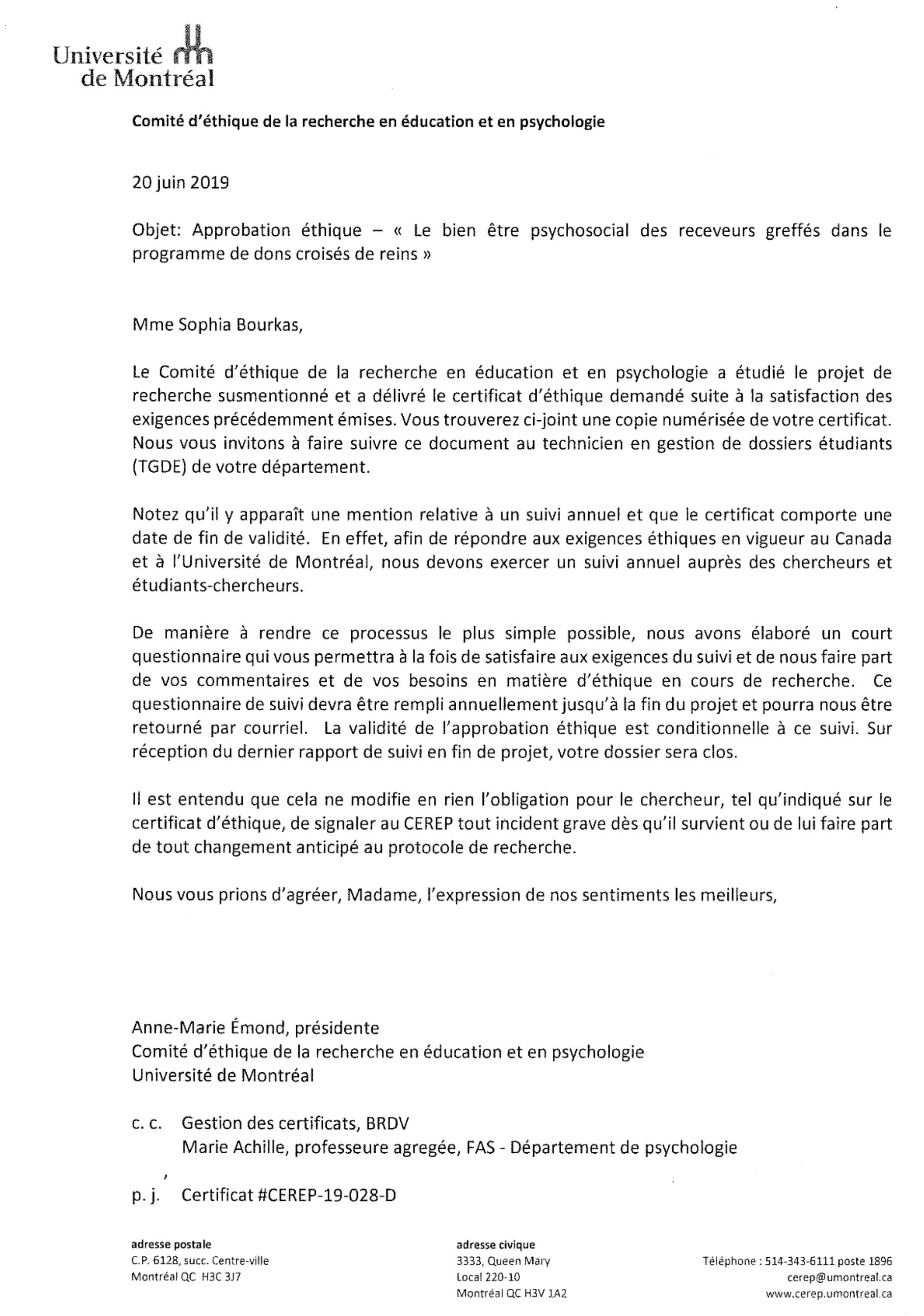
Appendix A: Ethics Committee Certificates of Approval

Article 1: Ethics Committee in Research and Education in Psychology, Université de Montréal



Université de Montréal

Comité d'éthique de la recherche en éducation et en psychologie

20 juin 2019

Objet: Approbation éthique – « Le bien être psychosocial des receveurs greffés dans le programme de dons croisés de reins »

Mme Sophia Bourkas,

Le Comité d'éthique de la recherche en éducation et en psychologie a étudié le projet de recherche susmentionné et a délivré le certificat d'éthique demandé suite à la satisfaction des exigences précédemment émises. Vous trouverez ci-joint une copie numérisée de votre certificat. Nous vous invitons à faire suivre ce document au technicien en gestion de dossiers étudiants (TGDE) de votre département.

Notez qu'il y apparaît une mention relative à un suivi annuel et que le certificat comporte une date de fin de validité. En effet, afin de répondre aux exigences éthiques en vigueur au Canada et à l'Université de Montréal, nous devons exercer un suivi annuel auprès des chercheurs et étudiants-chercheurs.

De manière à rendre ce processus le plus simple possible, nous avons élaboré un court questionnaire qui vous permettra à la fois de satisfaire aux exigences du suivi et de nous faire part de vos commentaires et de vos besoins en matière d'éthique en cours de recherche. Ce questionnaire de suivi devra être rempli annuellement jusqu'à la fin du projet et pourra nous être retourné par courriel. La validité de l'approbation éthique est conditionnelle à ce suivi. Sur réception du dernier rapport de suivi en fin de projet, votre dossier sera clos.

Il est entendu que cela ne modifie en rien l'obligation pour le chercheur, tel qu'indiqué sur le certificat d'éthique, de signaler au CEREP tout incident grave dès qu'il survient ou de lui faire part de tout changement anticipé au protocole de recherche.

Nous vous prions d'agréer, Madame, l'expression de nos sentiments les meilleurs,

Anne-Marie Émond, présidente
Comité d'éthique de la recherche en éducation et en psychologie
Université de Montréal

c. c. Gestion des certificats, BRDV
Marie Achille, professeure agregée, FAS - Département de psychologie

p. j. Certificat #CEREP-19-028-D

adresse postale
C.P. 6128, succ. Centre-ville
Montréal QC H3C 3J7

adresse civique
3333, Queen Mary
Local 220-10
Montréal QC H3V 1A2

Téléphone : 514-343-6111 poste 1896
cerep@umontreal.ca
www.cerep.umontreal.ca

Université de Montréal

Certificat no CEREP-19-028-D

Comité d'éthique de la recherche en éducation et en psychologie

CERTIFICAT D'APPROBATION ÉTHIQUE

Le Comité d'éthique de la recherche en éducation et en psychologie, selon les procédures en vigueur, en vertu des documents qui lui ont été fournis, a examiné le projet de recherche suivant et conclu qu'il respecte les règles d'éthique énoncées dans la Politique sur la recherche avec des êtres humains *de l'Université de Montréal.*

Projet	
Titre du projet	**Le bien être psychosocial des receveurs greffés dans le programme de dons croisés de reins**
Étudiante requérante	**Sophia Bourkas**, candidate au doctorat, FAS - Département de psychologie

Sous la direction de:	Marie Achille, professeure agregée, FAS - Département de psychologie, Université de Montréal

Financement	
Organisme	Fonds de Recherche du Québec - Société et Culture
Programme	Bourse au doctorat en recherche
Titre de l'octroi si différent	
Numéro d'octroi	262186
Chercheur principal	
No de compte	

MODALITÉS D'APPLICATION

Tout changement anticipé au protocole de recherche doit être communiqué au Comité qui en évaluera l'impact au chapitre de l'éthique.
Toute interruption prématurée du projet ou tout incident grave doit être immédiatement signalé au Comité.
Selon les règles universitaires en vigueur, un suivi annuel est minimalement exigé pour maintenir la validité de la présente approbation éthique, et ce, jusqu'à la fin du projet. Le questionnaire de suivi est disponible sur la page web du Comité.

Anne-Marie Émond, présidente
Comité d'éthique de la recherche en éducation et en psychologie
Université de Montréal

20 juin 2019
Date de délivrance

1er juillet 2020
Date de fin de validité

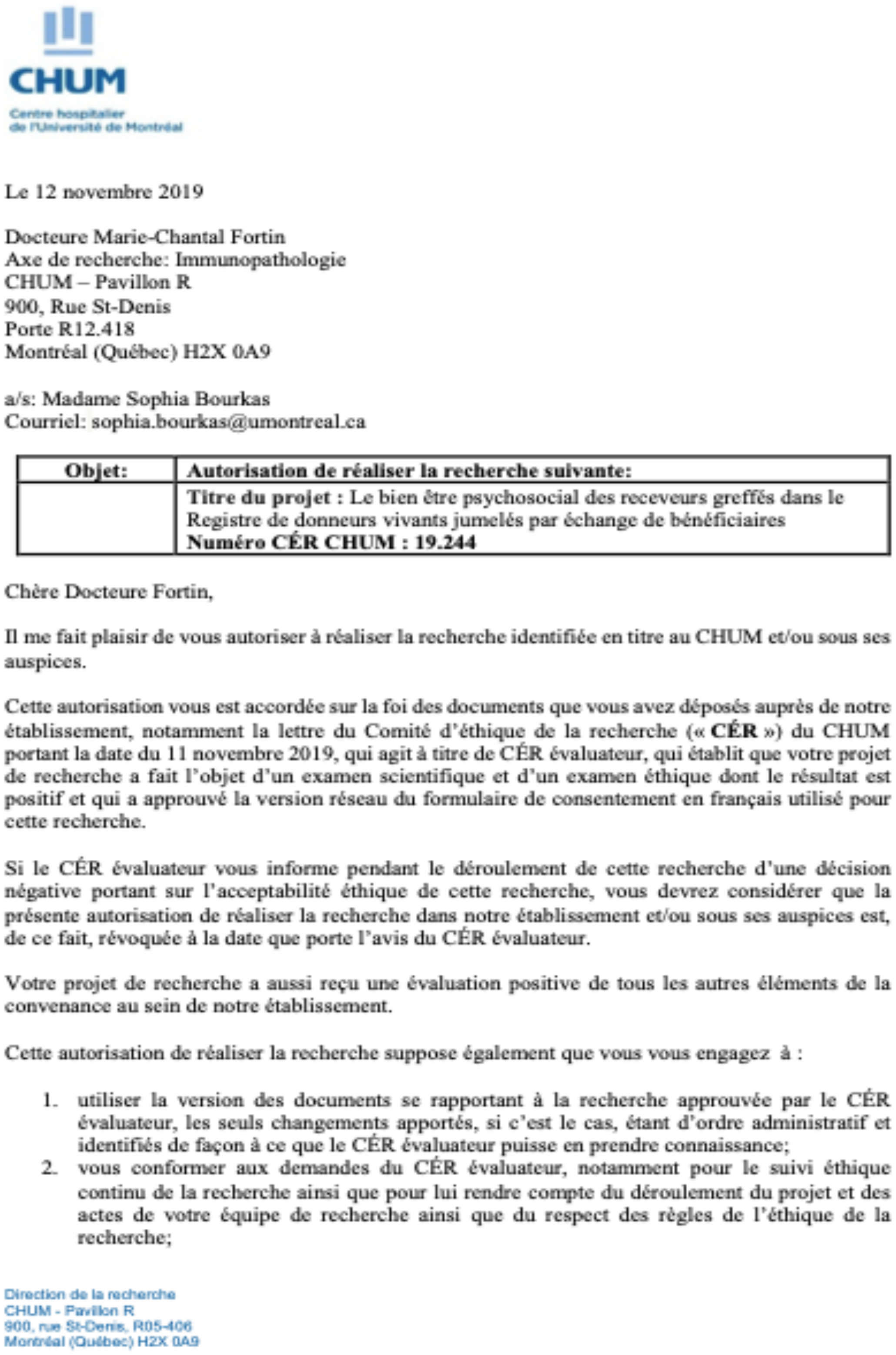
1er juillet 2020
Date du prochain suivi

adresse postale
C.P. 6128, succ. Centre-ville
Montréal QC H3C 3J7

adresse civique
3333, Queen Mary
Local 220-10
Montréal QC H3V 1A2

Téléphone : 514-343-6111 poste 1896
cerep@umontreal.ca
www.cerep.umontreal.ca

Article 1: Ethics Committee of the *Centre hospitalier de l'Université de Montréal*



CHUM
Centre hospitalier
de l'Université de Montréal

Le 12 novembre 2019

Docteure Marie-Chantal Fortin
Axe de recherche: Immunopathologie
CHUM – Pavillon R
900, Rue St-Denis
Porte R12.418
Montréal (Québec) H2X 0A9

a/s: Madame Sophia Bourkas
Courriel: sophia.bourkas@umontreal.ca

Objet:	**Autorisation de réaliser la recherche suivante:**
	Titre du projet : Le bien être psychosocial des receveurs greffés dans le Registre de donneurs vivants jumelés par échange de bénéficiaires **Numéro CÉR CHUM : 19.244**

Chère Docteure Fortin,

Il me fait plaisir de vous autoriser à réaliser la recherche identifiée en titre au CHUM et/ou sous ses auspices.

Cette autorisation vous est accordée sur la foi des documents que vous avez déposés auprès de notre établissement, notamment la lettre du Comité d'éthique de la recherche (« **CÉR** ») du CHUM portant la date du 11 novembre 2019, qui agit à titre de CÉR évaluateur, qui établit que votre projet de recherche a fait l'objet d'un examen scientifique et d'un examen éthique dont le résultat est positif et qui a approuvé la version réseau du formulaire de consentement en français utilisé pour cette recherche.

Si le CÉR évaluateur vous informe pendant le déroulement de cette recherche d'une décision négative portant sur l'acceptabilité éthique de cette recherche, vous devrez considérer que la présente autorisation de réaliser la recherche dans notre établissement et/ou sous ses auspices est, de ce fait, révoquée à la date que porte l'avis du CÉR évaluateur.

Votre projet de recherche a aussi reçu une évaluation positive de tous les autres éléments de la convenance au sein de notre établissement.

Cette autorisation de réaliser la recherche suppose également que vous vous engagez à :

1. utiliser la version des documents se rapportant à la recherche approuvée par le CÉR évaluateur, les seuls changements apportés, si c'est le cas, étant d'ordre administratif et identifiés de façon à ce que le CÉR évaluateur puisse en prendre connaissance;
2. vous conformer aux demandes du CÉR évaluateur, notamment pour le suivi éthique continu de la recherche ainsi que pour lui rendre compte du déroulement du projet et des actes de votre équipe de recherche ainsi que du respect des règles de l'éthique de la recherche;

3. conserver les dossiers de recherche pendant la période fixée par le CÉR évaluateur après la fin du projet, selon les règles de conservation de l'établissement, afin de permettre leur éventuelle vérification;
4. respecter le cadre règlementaire de l'établissement, notamment, s'il y a lieu, les modalités arrêtées au regard du mécanisme d'identification des participants à la recherche dans notre établissement, à savoir, la tenue à jour et la conservation de la liste à jour des participants de recherche recrutés sous les auspices de notre établissement. Cette liste devra nous être fournie sur demande.

L'autorisation qui vous est donnée ici de réaliser la recherche sous les auspices de notre établissement sera renouvelée sans autre procédure à la date indiquée par le CÉR évaluateur dans sa décision de renouveler son approbation éthique de cette recherche.

La présente autorisation peut être suspendue ou révoquée par le CHUM en cas de non-respect des conditions établies lors de notre examen de la convenance. Le CÉR évaluateur en sera alors informé.

Vous consentez également à ce que le CHUM communique aux autorités compétentes des renseignements personnels qui sont nominatifs au sens de la loi en présence d'un cas avéré de manquement à la conduite responsable en recherche de votre part lors de la réalisation de cette recherche.

Toute communication avec le soussigné concernant la présente autorisation à réaliser la recherche doit être acheminée ainsi :

- par courriel : convenance.recherche.chum@ssss.gouv.qc.ca
- par téléphone : (514) 890-8000, poste 30672.

Pour toutes questions, conseils ou soutien relativement aux aspects éthiques de votre projet de recherche, vous pouvez aussi solliciter l'appui du CÉR de notre établissement en vous adressant aux coordonnées suivantes :

- par courriel : ethique.recherche.chum@ssss.gouv.qc.ca
- par téléphone : 514 890-8000, poste 14485.

En terminant, je vous demanderais de toujours mentionner dans votre correspondance au sujet de ce projet de recherche le numéro attribué à votre demande par le CHUM, soit **19.244**.

En vous remerciant de votre contribution à la mission de recherche de notre établissement, je vous prie d'agréer, Chère Docteure Fortin, l'expression de mes sentiments les meilleurs.

Vincent Poitout, D.V.M., Ph.D, FCAHS
Personne mandatée par le CHUM
pour autoriser la réalisation des recherches

c.c. :

- Me Marie-Josée Bernardi, Présidente du CÉR du CHUM

Article 2: Ethics Committee of the *Centre hospitalier de l'Université de Montréal*

CHUM

Comité d'éthique de la recherche du CHUM
Pavillon R, 900 rue St-Denis, 3e étage
Montréal (Québec) H2X 0A9

Le 19 mars 2020

Madame Marie-Chantal Fortin
Axe de recherche: insulte tissulaire, infection, immunité et inflammation

a/s: M. Fabian-Andrès Ballesteros Gallego
courriel: fabian.ballesteros.chum@ssss.gouv.qc.ca

Objet:	**MP-02-2020-8637, 19.244 – Accusé réception d'un formulaire (F2 - 53578)**
	Le bien être psychosocial des receveurs greffés dans le Registre de donneurs vivants jumelés par échange de bénéficiaires

Madame,

La présente est pour vous informer que le formulaire F2 - 53578 que vous nous avez soumis est complet et conforme aux règles applicables. Le CÉR du CHUM qui agit à titre de CÉR évaluateur pour le projet en titre en accuse réception.

Vous souhaitant la meilleure des chances dans la poursuite de vos travaux, nous vous prions d'accepter, Madame, nos salutations distinguées.

Me Marie-Josée Bernardi, avocate
Chef du Bureau de l'éthique
Présidente du Comité d'éthique de la recherche

Appendix B: Sociodemographic Questionnaire

Article 1

Université de Montréal

Sociodemographic Questionnaire

Please answer the following questions by filling in one circle or providing a written response, where applicable.

1. Please indicate your gender:

2. Please indicate your age:

3. Do you currently have children under the age of 18 living in your household?

If you answered "yes," how many children under the age of 18 live in your household?

____

4. Which best describes your marital status?
    ○ Single, not married
    ○ In a relationship
    ○ Married
    ○ Living with a partner
    ○ Separated
    ○ Divorced
    ○ Widowed
    ○ Prefer not to answer

5. Which best describes your education level?
    ○ Elementary school
    ○ High school
    ○ Cegep or some post-secondary
    ○ University – Bachelor's degree
    ○ University – Graduate studies
    ○ University – Post-graduate studies

6. Which best describes your work status?
    ○ Unemployed
    ○ Employed part-time
    ○ Employed full-time

7. Which best describes your annual household income?
    ○ < $25,000

- ○ $25,000 - $49,000
- ○ $50,000 - $74,000
- ○ $75,000 - $99,000
- ○ ≥ $100,000

8. What is your relationship with your known donor?

Your donor is:

- ○ Your parent
- ○ Your sibling
- ○ Your child
- ○ Your partner
- ○ Other relative
- ○ Your friend

9. What was the date of your last dialysis treatment? Please specify the month and year.

10. What was the date of your transplantation through the Kidney Paired exchange program? Please specify the month and year.

11. Did you experience complications after your transplantation?

12. How many days did you spend in the hospital at the time of your transplantation?

13. Have you undergone treatment for an episode of acute rejection in the last 12 months?

14. What type of immunosuppressive medication are you taking? What is the dosage and the schedule of your medication regimen?

Université de Montréal

Sociodemographic Questionnaire

Please answer the following questions by filling in one circle or providing a written response, where applicable.

1. Please indicate your gender:

2. Please indicate your age:

3. Do you currently have children under the age of 18 living in your household?

   If you answered "yes," how many children under the age of 18 live in your household?

   ____

4. Which best describes your marital status?
   - ○ Single, not married
   - ○ In a relationship
   - ○ Married
   - ○ Living with a partner
   - ○ Separated
   - ○ Divorced
   - ○ Widowed
   - ○ Prefer not to answer

5. Which best describes your education level?
   - ○ Elementary school
   - ○ High school
   - ○ Cegep or some post-secondary
   - ○ University – Bachelor's degree
   - ○ University – Graduate studies
   - ○ University – Post-graduate studies

6. Which best describes your work status?
   - ○ Unemployed
   - ○ Employed part-time
   - ○ Employed full-time

7. Which best describes your annual household income?
   - ○ < $25,000
   - ○ $25,000 - $49,000
   - ○ $50,000 - $74,000

○ $75,000 - $99,000
○ ≥ $100,000

8. What is your relationship with your donor?

Your donor is:

○ Your parent
○ Your sister or brother
○ Your child
○ Your partner
○ Another member of your family
○ Your friend
○ Deceased donor (unknown)
○ Other. Please specify: ______________

9. What was the date of your last dialysis treatment? Please specify the month and year.

10. What was the date of your transplantation? Please specify the month and year.

11. Did you experience complications after your transplantation?

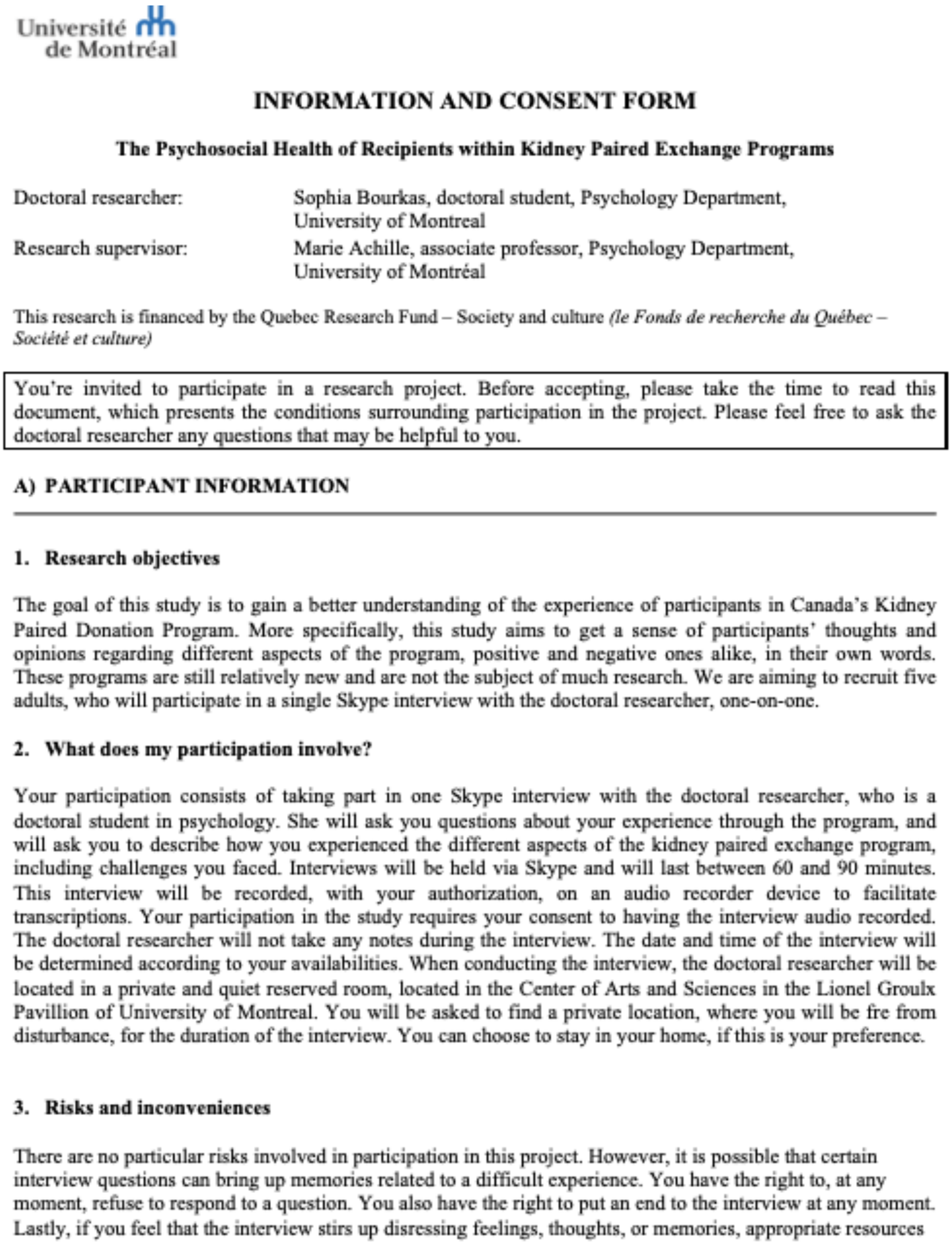
12. How many days did you spend in the hospital at the time of your transplantation?

13. Have you undergone treatment for an episode of acute rejection in the last 12 months?

14. What type of immunosuppressive medication are you taking? What is the dosage and the schedule of your medication regimen?

Appendix C: Information and Consent Form

Article 1: Information and Consent Form, Ethics Committee in Research and Education in Psychology, Université de Montréal



Université
de Montréal

INFORMATION AND CONSENT FORM

The Psychosocial Health of Recipients within Kidney Paired Exchange Programs

Doctoral researcher:	Sophia Bourkas, doctoral student, Psychology Department, University of Montreal
Research supervisor:	Marie Achille, associate professor, Psychology Department, University of Montréal

This research is financed by the Quebec Research Fund – Society and culture *(le Fonds de recherche du Québec – Société et culture)*

You're invited to participate in a research project. Before accepting, please take the time to read this document, which presents the conditions surrounding participation in the project. Please feel free to ask the doctoral researcher any questions that may be helpful to you.

A) PARTICIPANT INFORMATION

1. Research objectives

The goal of this study is to gain a better understanding of the experience of participants in Canada's Kidney Paired Donation Program. More specifically, this study aims to get a sense of participants' thoughts and opinions regarding different aspects of the program, positive and negative ones alike, in their own words. These programs are still relatively new and are not the subject of much research. We are aiming to recruit five adults, who will participate in a single Skype interview with the doctoral researcher, one-on-one.

2. What does my participation involve?

Your participation consists of taking part in one Skype interview with the doctoral researcher, who is a doctoral student in psychology. She will ask you questions about your experience through the program, and will ask you to describe how you experienced the different aspects of the kidney paired exchange program, including challenges you faced. Interviews will be held via Skype and will last between 60 and 90 minutes. This interview will be recorded, with your authorization, on an audio recorder device to facilitate transcriptions. Your participation in the study requires your consent to having the interview audio recorded. The doctoral researcher will not take any notes during the interview. The date and time of the interview will be determined according to your availabilities. When conducting the interview, the doctoral researcher will be located in a private and quiet reserved room, located in the Center of Arts and Sciences in the Lionel Groulx Pavillion of University of Montreal. You will be asked to find a private location, where you will be fre from disturbance, for the duration of the interview. You can choose to stay in your home, if this is your preference.

3. Risks and inconveniences

There are no particular risks involved in participation in this project. However, it is possible that certain interview questions can bring up memories related to a difficult experience. You have the right to, at any moment, refuse to respond to a question. You also have the right to put an end to the interview at any moment. Lastly, if you feel that the interview stirs up disressing feelings, thoughts, or memories, appropriate resources will be provided to you.

4. Advantages and benefits

There are no particular advantages to participating in this project. However, you're contributing to the development of a better understanding of participants' particular needs in kidney paired exchange programs. Knowledge of their needs will influence the care and support services they will be offered in the future.

5. Confidentiality

All personal information you provide will remain confidential. No information allowing you to be identified will be published. Each participant will be given a code. Only the doctoral researcher and her research supervisor will be able to link the participant to their corresponding code to know their identity. All documents in paper copy will be conserved in a filing cabinet under lock and key in the research laboratory of the doctoral researcher's research supervisor (located in the Department of Psychology at University of Montreal, Pavillion Marie-Victorin, room D-325). All electronic files, including audio recordings, will be stored on a password-protected USB key. This USB key will also be stored in the locked filing cabinet located in the lab of the doctoral researcher. All audio recordings and personal information will be destroyed 7 years after the end of the study.

6. Compensation

To thank you for your participation, an e-gift card with a value of 20 $ for Tim Hortons will be sent to you via email the day after your interview.

7. Right to withdraw

Your participation in this project is entirely voluntary and you can, at any moment, withdraw from the research simply by verbal indication, without having to justify your decision, without any consequence to you. If you decide to withdraw from the study, you can reach the doctoral researcher at the telephone number inscribed below.

At your request, all study information concerning you can also be destroyed. However, once the publication process has started, it will be impossible to destroy the analyses and results.

B) CONSENT

Participant Declaration

- I understand that I can take the time I need to reflect before giving my consent to participate in the research study
- I can ask questions to the doctoral researcher and request satisfying responses.
- I understand that by participating in the study, I do not renounce any of my rights nor absolve the doctoral researcher of her responsibilities.
- I understand that the interview will be recorded in audio format, and I give my consent for the audio recording of my interview.
- I have familiarized myself with the information in the present consent form and I agree to participate in the research project.

Participant signature: ____ Date: ___________________________

Name: ____ Surname: ________________________________

Engagement of the doctoral researcher

I have explained to the participant the conditions of participating in the research study. I have responded to the best of my knowledge to the questions asked and have ensured that the participant has understood the information provided. I agree to respect and adhere to the agreement contained in the present information and consent form.

Doctoral researcher signature: _______________________________ Date: _____________________________
(or her representative)

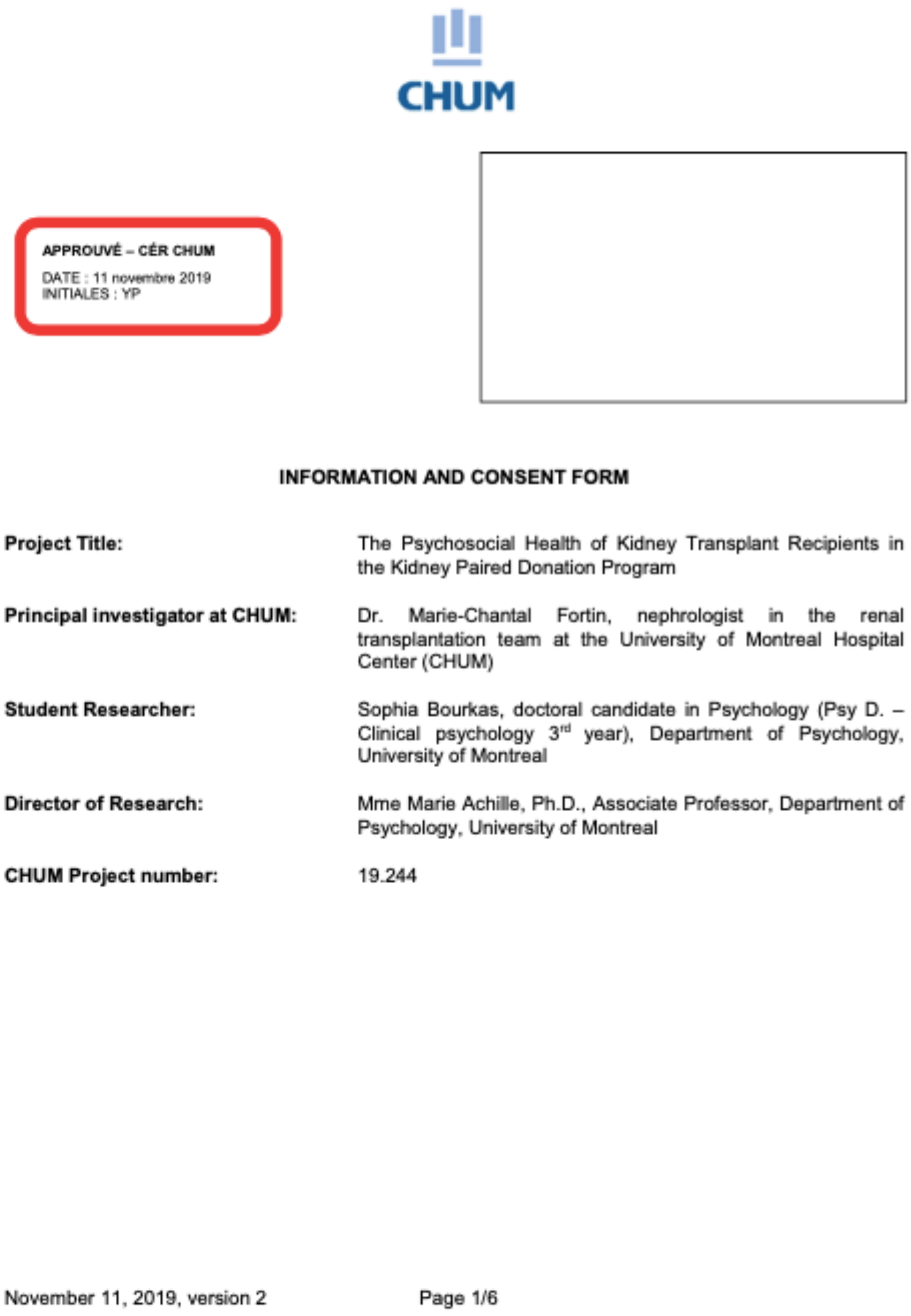
Name: ____ Surname: __________________________________

For all questions related to the study, or to withdraw from the study, please contact Sophia Bourkas at the following number or at the email address sophia.bourkas@umontreal.ca.

For any concerns regarding your rights or the responsibilities of the researcher relative to your participation in the study, you can contact the Ethics Committe on Research in Education and Psychology by email: cerep@umontreal.ca or by telephone at 514 343-6111 extension 1896 or consult the web site http://recherche.umontreal.ca/participants.

All complaints concerning your participation to this study can be addressed to the ombudsman of University of Montreal by calling 514 343-2100 or by email communication to ombudsman@umontreal.ca **(the ombudsman accepts collect calls).**

Article 1: Consent Form, Centre hospitalier de l'Université de Montréal



CHUM

APPROUVÉ – CÉR CHUM
DATE : 11 novembre 2019
INITIALES : YP

INFORMATION AND CONSENT FORM

Project Title:	The Psychosocial Health of Kidney Transplant Recipients in the Kidney Paired Donation Program
Principal investigator at CHUM:	Dr. Marie-Chantal Fortin, nephrologist in the renal transplantation team at the University of Montreal Hospital Center (CHUM)
Student Researcher:	Sophia Bourkas, doctoral candidate in Psychology (Psy D. – Clinical psychology 3rd year), Department of Psychology, University of Montreal
Director of Research:	Mme Marie Achille, Ph.D., Associate Professor, Department of Psychology, University of Montreal
CHUM Project number:	19.244

November 11, 2019, version 2 Page 1/6

PREAMBLE

We are inviting you to participate in this research project because you have received a kidney transplant through Canada's Kidney Paired Donation program (KPD). However, before accepting to participate in this project and signing this Information and Consent Form, please take the time you need to read, understand, and carefully consider the instructions and information it contains.

This form may contain words that you are not familiar with. We encourage you to share any questions that you may have with the principal researcher, student researcher, or other members affiliated with the project. We also encourage you to ask them to explain any words, terms, or instructions that are not clear.

NATURE AND OBJECTIVE OF THE PROJECT

The objective of this research project is to gain a better understanding of the experience of individuals who have received a kidney transplant through the KPD program. The psychosocial implications of the KPD program remain under-studied, so little is known about what it's like for participants to go through it. This study will aim to identify some of the factors that impacted the decision to participate in KPD, relationships with the donor, some worries and expectations about the program, and what the post-transplantation period was like, in participants' own words. More specifically, this project aims to gather an in-depth understanding of the personal experience and unique perspective of each transplant recipient. The study results will describe and shed light on this experience, and may contribute to helping future transplant recipients in the KPD program.

NUMBER OF PARTICIPANTS AND DURATION OF PARTICIPATION

Ten (10) people who have received a kidney transplant through the CHUM's Nephrology Clinic via the KPD program will participate in this research study. The duration of your participation will be between 60 to 90 minutes. The total duration of the research study will be 10 months.

NATURE OF PARTICIPATION AND STUDY PROCEDURE

If you accept to participate in this research study and sign this Information and Consent Form, your participation will consist of:

- Completing a short Sociodemographic Questionnaire in order to provide us with some sociodemographic information such as your name, your sex, your age and your employment status.
- Meeting the student researcher for one individual interview that will last between 60 to 90 minutes. This interview will focus on your experience with the KPD program. The positive aspects, as well as the challenges you may have encountered through this program will be covered. This interview will take place either in a private room at the CHUM on the day of your follow-up at the Nephrology Clinic, or via Skype in a location of your choice. The date of the interview will be determined according to your availabilities and preferences.
- Should you perceive a question difficult to answer, you have the option to not respond. Please note that there are no right or wrong answers. The interview will be recorded on audio device in order to facilitate its transcription afterwards.

RISKS AND INCONVENIENCES

There are no particulr risks involved in participating in this project. It is possible, however, that certain questions may stir up memories linked to a difficult experience. You may, at any moment, decide not to respond to a question or even choose to end the interview. Moreover, should the interview stir up a difficult experience, we will provide you with the appropriate resources capable of providing you with the assistance and support you require. You can end the interview at any moment. The student researcher will offer to reschedule the interview at another moment, if you wish to do so.

ADVANTAGES

There are no particular advantages to participating in this project. However, your participation would be a contribution to a better, more refined understanding of the need of participants in KPD programs.

CONFIDENTIALITY

During your participation in this research project, the student reseacher as well as other members of the research team will gather some information that pertains to you and compile this information in a research file, required to meet scientific objectives of this project.

Your file could contain information such as your name, your sex, your date-of-birth and your ethnicity.

All the information that is gathered in your file will remain confidential, within the parameters of the law. You will only be identified by a code number. The key to the code that links your name to your research file will be kept only in posession of the principcal researcher of this project.

This information will be conserved for at least 10 years by the principal researcher of this research project.

This information may be published or become the focus of scientific discussions, but any identifying information will not be revealed, therefore it will not be possible to identify you.

You have the right to consult your research file to verify the information gathered and have it corrected, if needed.

DIFFUSION OF THE GENERAL STUDY RESULTS

The general results of this study may be shared with you, upon your request to the principal researcher at the end of the study.

COMPENSATION

To thank you for your participation, an electronic gift card for Tim Hortons with a value of $20 will be sent to you by email the day after your interview.

IN CASE OF PREJUDICE

By accepting to participate in this research project, you are not in any way renouncing to your rights and you are not exempting the principcal researcher of this project, nor the establishment, of their civil and professional responsibility.

VOLONTARY PARTICIPATION AND RIGHT TO WITHDRAW

Your participation in this project is entirely voluntary and you may, at any moment, choose to withdraw from the study upon the provision of verbal or written notice, and without having to justify your decision, without any consequences. If you decide to withdraw from the study, please contact the student researcher by phone or by email, at the number or email address indicated below.

Your decision to withdraw from the study will have no consequences, nor will it impact the quality of care and services that you have the right to receive, or your relationship with the teams providing these services.

CONTACT INFORMATION

If you have any questions or experience problems associated with this research project, or if you wish to withdraw, you can communicate with the principal researcher, Dr. Marie-Chantal Fortin, at the following number: (514) 890-8000, extension 25712 (between 9:00 AM and 5:00 PM, Monday to Friday), or with the student researcher, Sophia Bourkas, at the following number: (between 9:00 AM and 5:00 PM, from Monday to Friday), or by email via the following address: sophia.bourkas@umontreal.ca

To address any preoccupations or concerns about your rights or the responsibiliy of the researchers of the research project with regards to your participation, you can contact the Service Quality and Complaints Commissionner (Ombudsman) of the CHUM at 514-890-8484.

SIGNATURE

I have read and understood this Information and Consent Form. The research project and this Information and Consent Form were both clearly explained to me. My questions were answered, and I was given time to make a decision regarding my participation. After some reflection, I consent to participate in this research project, in accordance with the conditions outlined.

Name (in block letters)	Signature of the participant	Date

SIGNATURE OF THE PERSON THAT OBTAINS CONSENT, IF DIFFERENT THAN THE PRINCIPAL RESEARCHER OF THE RESEARCH PROJECT

I explained the research project and this Information and Consent Form to the participant, and I answered the questions that they asked me.

Name (in block letters)	Signature of the person obtaining Consent	Date

COMMITMENT OF OF THE PRINCIPAL INVESTIGATOR

I confirm that the research project and Information and Consent Form were explained to the participant, and that their questions were answered.

I agree to, with the research team, adhere to the conditions described in this Information and Consent Form, and to provide the participant with a signed and dated copy.

Name (in block letters)	Signature of the principal investigator	Date

SIGNATURE OF A WITNESS

OUI □ **NON** □

The signature of a witness is required for the following reasons:

- ☐ Difficulty or inability to read – The person (impartial witness) that provides their signature below attests to having read the Information and Consent Form and states that the participant was provided with a precise description of the research project, that they appear to have understood.
- ☐ Lack of familiarity with the language of the Information and Consent Form – The person who has provided their signature below has taken on the role of translator in order to share the content of the form with the participant during the process of obtaining their consent.

Name (in block letters)	Signature of the witness	Date

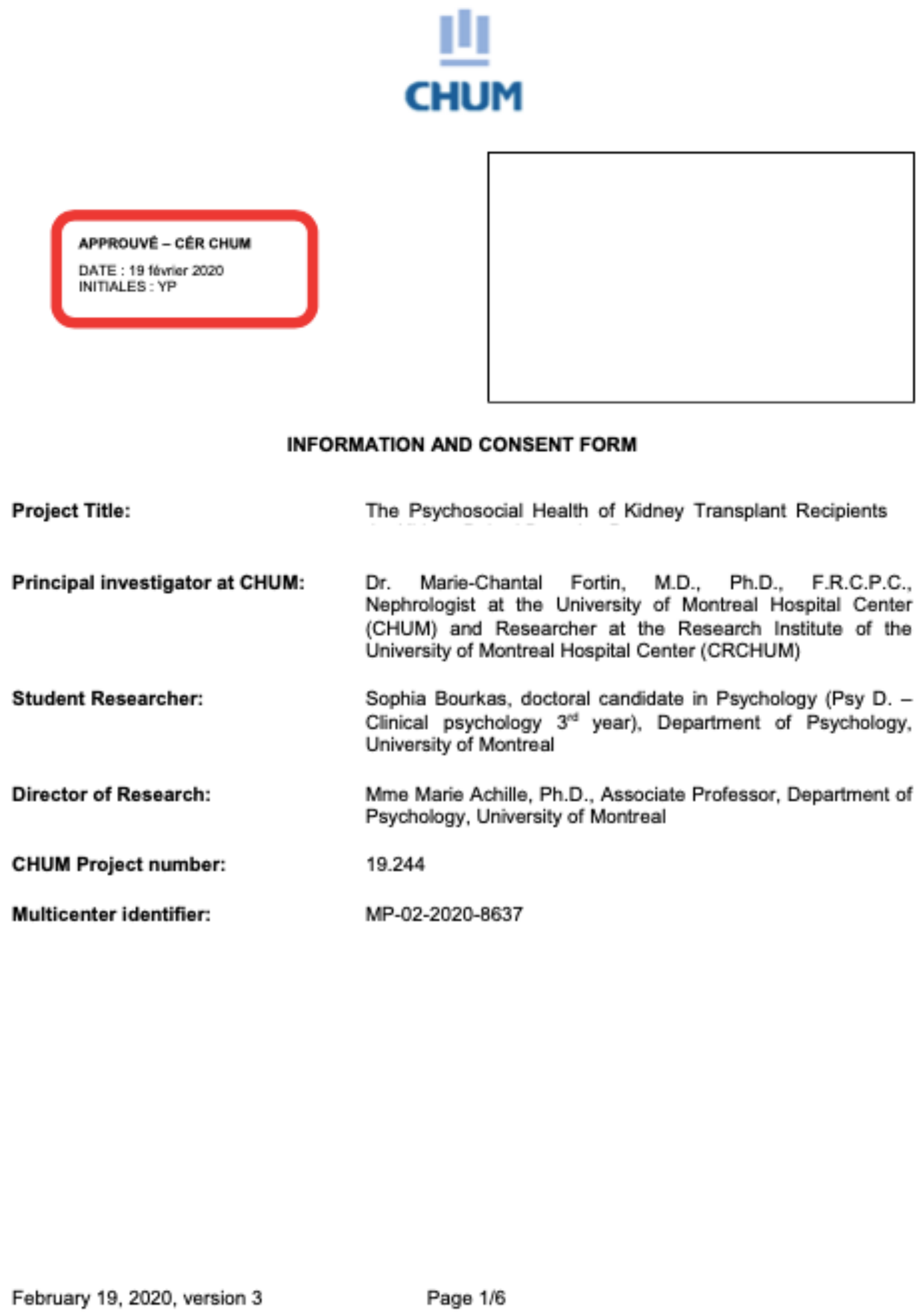
Please note:

Where applicable, the participant's research file should include additional information on assistance provided during the process of obtaining consent.

APPROVAL BY THE RESEARCH ETHICS COMMITTEE

The Research Ethics Committee of the CHUM has approved the research project and will monitor it.

Article 2: Consent Form, Centre hospitalier de l'Université de Montréal



CHUM

APPROUVÉ – CÉR CHUM
DATE : 19 février 2020
INITIALES : YP

INFORMATION AND CONSENT FORM

Project Title:	The Psychosocial Health of Kidney Transplant Recipients
Principal investigator at CHUM:	Dr. Marie-Chantal Fortin, M.D., Ph.D., F.R.C.P.C., Nephrologist at the University of Montreal Hospital Center (CHUM) and Researcher at the Research Institute of the University of Montreal Hospital Center (CRCHUM)
Student Researcher:	Sophia Bourkas, doctoral candidate in Psychology (Psy D. – Clinical psychology 3rd year), Department of Psychology, University of Montreal
Director of Research:	Mme Marie Achille, Ph.D., Associate Professor, Department of Psychology, University of Montreal
CHUM Project number:	19.244
Multicenter identifier:	MP-02-2020-8637

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PREAMBLE

We are inviting you to participate in this research project because you have received a kidney transplant. However, before accepting to participate in this project and signing this Information and Consent Form, please take the time you need to read, understand, and carefully consider the instructions and information it contains.

This form may contain words that you are not familiar with. We encourage you to share any questions that you may have with the principal researcher, student researcher, or other members affiliated with the project. We also encourage you to ask them to explain any words, terms, or instructions that are not clear.

NATURE AND OBJECTIVE OF THE PROJECT

The objective of this research project is to gain a better understanding of kidney recipients' experience of the transplantation process in different contexts : directed donation, deceased donation, and the KPD program. The psychosocial implications of transplantation remain under-studied, so little is known about what it's like for participants to go through it. This study will aim to understand the relationships wit the donor, where applicable, as well as some worries and expectations about transplantation, and what the post-transplantation period was like, in participants' own words. More specifically, this project aims to gather an in-depth understanding of the personal experience and unique perspective of each transplant recipient. The study results will describe and shed light on this experience, and may contribute to helping future transplant recipients, including those in the KPD program.

NUMBER OF PARTICIPANTS AND DURATION OF PARTICIPATION

Between 15 and 20 participants who have received a kidney transplant through the CHUM's Nephrology clinic and the MUHC's Nephrology Clinic will participate in this research study. The duration of your participation will be between 60 to 90 minutes. The total duration of the research study will be 10 months.

NATURE OF PARTICIPATION AND STUDY PROCEDURE

If you accept to participate in this research study and sign this Information and Consent Form, your participation will consist of:

- Completing a short Sociodemographic Questionnaire in order to provide us with some sociodemographic information such as your name, your sex, your age and your employment status.
- Meeting the student researcher for one individual interview that will last between 60 to 90 minutes. This interview will focus on your experience with transplantation. The positive aspects, as well as the challenges you may have encountered through will be covered. This interview will take place either in a private room at the CHUM on the day of your follow-up at the Nephrology Clinic, or via Skype in a location of your choice. The date of the interview will be determined according to your availabilities and preferences.
- Should you perceive a question difficult to answer, you have the option to not respond. Please note that there are no right or wrong answers. The interview will be recorded on audio device in order to facilitate its transcription afterwards.

RISKS AND INCONVENIENCES

There are no particular risks involved in participating in this project. It is possible, however, that certain questions may stir up memories linked to a difficult experience. You may, at any moment, decide not to respond to a question or even choose to end the interview. Moreover, should the interview stir up a difficult experience, we will provide you with the appropriate resources capable of providing you with the assistance and support you require. You can end the interview at any moment. The student researcher will offer to reschedule the interview at another moment, if you wish to do so.

ADVANTAGES

There are no particular advantages to participating in this project. However, your participation would be a contribution to a better, more refined understanding of the need of transplant recipients.

CONFIDENTIALITY

During your participation in this research project, the student reseacher as well as other members of the research team will gather some information that pertains to you and compile this information in a research file, required to meet scientific objectives of this project.

Your file could contain information such as your name, your sex, your date-of-birth and your ethnicity.

All the information that is gathered in your file will remain confidential, within the parameters of the law. You will only be identified by a code number. The key to the code that links your name to your research file will be kept only in posession of the principcal researcher of this project.

This information will be conserved for at least 10 years by the principal researcher of this research project.

This information may be published or become the focus of scientific discussions, but any identifying information will not be revealed, therefore it will not be possible to identify you.

You have the right to consult your research file to verify the information gathered and have it corrected, if needed.

DIFFUSION OF THE GENERAL STUDY RESULTS

The general results of this study may be shared with you, upon your request to the principal researcher at the end of the study.

COMPENSATION

To thank you for your participation, an electronic gift card for Tim Hortons with a value of $20 will be sent to you by email the day after your interview.

IN CASE OF PREJUDICE

By accepting to participate in this research project, you are not in any way renouncing to your rights and you are not exempting the principcal researcher of this project, nor the establishment, of their civil and professional responsibility.

VOLONTARY PARTICIPATION AND RIGHT TO WITHDRAW

Your participation in this project is entirely voluntary and you may, at any moment, choose to withdraw from the study upon the provision of verbal or written notice, and without having to justify your decision, without any consequences. If you decide to withdraw from the study, please contact the student researcher by phone or by email, at the number or email address indicated below.

Your decision to withdraw from the study will have no consequences, nor will it impact the quality of care and services that you have the right to receive, or your relationship with the teams providing these services.

CONTACT INFORMATION

If you have any questions or experience problems associated with this research project, or if you wish to withdraw, you can communicate with the principal researcher, Dr. Marie-Chantal Fortin, at the following number: (514) 890-8000, extension 25712 (between 9:00 AM and 5:00 PM, Monday to Friday), or with the student researcher, Sophia Bourkas, at the following number: (between 9:00 AM and 5:00 PM, from Monday to Friday), or by email via the following address: sophia.bourkas@umontreal.ca

To address any preoccupations or concerns about your rights or the responsibiliy of the researchers of the research project with regards to your participation, you can contact the Service Quality and Complaints Commissionner (Ombudsman) of the CHUM at 514-890-8484.

SIGNATURE

I have read and understood this Information and Consent Form. The research project and this Information and Consent Form were both clearly explained to me. My questions were answered, and I was given time to make a decision regarding my participation. After some reflection, I consent to participate in this research project, in accordance with the conditions outlined.

Name (in block letters)   Signature of the participant   Date

SIGNATURE OF THE PERSON THAT OBTAINS CONSENT, IF DIFFERENT THAN THE PRINCIPAL RESEARCHER OF THE RESEARCH PROJECT

I explained the research project and this Information and Consent Form to the participant, and I answered the questions that they asked me.

Name (in block letters)   Signature of the person obtaining consent   Date

COMMITMENT OF OF THE PRINCIPAL INVESTIGATOR AT THE CHUM

I confirm that the research project and Information and Consent Form were explained to the participant, and that their questions were answered.

I agree to, with the research team, adhere to the conditions described in this Information and Consent Form, and to provide the participant with a signed and dated copy.

Name (in block letters)   Signature of the principal investigator at the CHUM   Date

SIGNATURE OF A WITNESS

OUI ☐ **NON** ☐

The signature of a witness is required for the following reasons:

- ☐ Difficulty or inability to read – The person (impartial witness) that provides their signature below attests to having read the Information and Consent Form and states that the participant was provided with a precise description of the research project, that they appear to have understood.
- ☐ Lack of familiarity with the language of the Information and Consent Form – The person who has provided their signature below has taken on the role of translator in order to share the content of the form with the participant during the process of obtaining their consent.

Name (in block letters)   Signature of the witness   Date

Please note:

Where applicable, the participant's research file should include additional information on assistance provided during the process of obtaining consent.

APPROVAL BY THE RESEARCH ETHICS COMMITTEE

The Research Ethics Committee of the CHUM has approved the research project and will monitor it at all participating institutions in the health and social service network in Quebec.

Appendix D: Interview Guide

Article 1

Preamble

Thank you for choosing to take part in the interview today. The questions that we'll be covering today will span several areas. The first is about your overall experience with transplantation; the next area is about your relationship with your known donor. The third is about your relationship with the anonymous donor. The last area will involve questions on how you think and feel about your new kidney.

The purpose of this interview is to get your perceptions of your experiences with KPD, your thoughts and feelings towards your donors, known/ anonymous, and towards your kidney. Please keep in mind that there are no right or wrong, or desirable or undesirable answers. I invite you to say what you really think and how you really feel. You may withdraw from the interview at any time, if you wish.

If it is okay with you, I will begin tape-recording our conversation. Do you have any questions? Are you ready to begin?

Interview Guide:
Dimensions within transplantation that may affect recipients' psychosocial health

A. Experience of renal dialysis and global experience of the transplantation process

1) Could you give me a brief history of your kidney problem from when it started until you were listed for kidney transplantation?

2) Did you do dialysis, and how would you describe your experience with renal dialysis?

3) How did you come to have a living donor?

4) How did you come to be a candidate in KPD?

5) What was your reaction when KPD was suggested to you as an option?
Sub-questions: How and when were you informed? How did you make the decision to participate?

6) How would you describe your experience with KPD?

B. Relationship with the known donor

7) What was your relationship with your donor like before your transplantation?
Sub-questions: Did you see your donor differently? Do you think your donor sees you differently? Were there phases when you noticed differences in how you treated each other?

8) How would you currently describe your relationship with your known donor?
Sub-question: Has your relationship changed?

C. Relationship with the anonymous donor

9) What do you think of the anonymity rules that frame your relationship with your anonymous donor?

10) How often do you think about your anonymous donor?
Sub-questions: What are some of the thoughts that you have? What are the images that come to mind? How do you feel as we talk about your anonymous donor?

11) How do you represent your anonymous donor?
Sub-questions: How would you describe them? Have you built an image of your anonymous donor? Do you think of who they are, or how they are, and some or their characteristics?

D. Level of psychological organ integration

12) Do you represent your kidney differently now compared to after your transplantation?
Sub-question: Has your representation changed or evolved in different phases after the transplantation? Did you at first perceive it as belonging to someone else, directly after transplantation?

13) Can you describe how you represent your kidney today?
Sub-questions: What image comes to mind? What words come to mind? In this moment, do you have an image in mind?

Article 2

Preamble

Thank you for choosing to take part in the interview today. The questions that we'll be covering today will span several areas. The first is about your overall experience with transplantation, and the next area is about your relationship with your known / anonymous donor.

The purpose of this interview is to get your perceptions of your experiences with transplantation and your thoughts and feelings towards your donors, known/ anonymous. Please keep in mind that there are no right or wrong, or desirable or undesirable answers. I invite you to say what you really think and how you really feel. You may withdraw from the interview at any time, if you wish. If it is okay with you, I will begin tape-recording our conversation. Do you have any questions? Are you ready to begin?

Interview Guide: Relationship with the donor

A. Experience of renal dialysis and global experience of the transplantation process

1) Could you give me a brief history of your kidney problem from when it started until you were listed for kidney transplantation?

2) Did you do dialysis, and how would you describe your experience with renal dialysis?

3) Overall, how would you describe your experience with living donation/ deceased donation?

B. Relationship with the known donor (for recipients of living direct donation)

4) How would you describe your relationship with your known donor?
Sub-questions: Has your relationship changed? Did you see your donor differently? Do you think your donor sees you differently? Were there phases when you noticed differences in how you treated each other?

C. Relationship with the anonymous donor (for recipients of deceased donation)

5) What do you think of the anonymity rules that frame your relationship with your anonymous donor?

6) Are you satisfied with the amount of contact you've had with the donor family?
Sub-question: Would you like to have been able to meet the donor family?

7) How often do you think about your anonymous donor?

8) How do you represent your anonymous donor?
Sub-questions: How would you describe them? It could be a thought, image, feeling, etc. Anything that comes to mind.