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Donation vivante de rein: trajectoire de transplantation, expérience relationnelle et enjeux éthiques et méthodologiques d'une recherche qualitative impliquant des dyades donneur-receveur

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RÉSUMÉ

La présente thèse poursuit l'objectif général de mieux comprendre l'expérience de la transplantation d'organe de la perspective de dyades comprenant un donneur et un receveur d'une donation vivante de rein. Pour ce faire, nous proposons une exploration en profondeur de la trajectoire de transplantation et des enjeux relationnels des donneurs et des receveurs. Un second objectif, qui s'est développé au cours de la recherche, est de contribuer à une meilleure compréhension des enjeux entourant la recherche qualitative impliquant des dyades.

Cette thèse est présentée sous la forme de trois articles. Le premier article vise, par le biais de la méthode du méta-résumé, à dresser un portrait le plus complet possible du processus de donation tel qu'il avait été examiné à ce jour par les écrits empiriques qualitatifs disponibles, et à mettre en lumière les aspects qui avaient encore peu été appréhendés par les chercheurs, notamment l'importance de considérer conjointement au sein d'une même recherche des donneurs et des receveurs d'une donation vivante de rein.

Le deuxième article a pour but d'explorer en profondeur l'expérience vécue pour des dyades de donneurs et de receveurs en contexte de donation vivante de rein, et en particulier la trajectoire de transplantation ainsi que les enjeux relationnels. Des entrevues qualitatives ont été menées auprès de cinq dyades (donc cinq donneurs et cinq receveurs). L'analyse phénoménologique interprétative des données recueillies propose un portrait de la trajectoire de transplantation, soit (a) l'expérience de la maladie du receveur, (b) l'expérience d'offrir et d'accepter un rein, (c) la période des tests, (d) la transplantation d'organe à proprement parler et finalement (e) la période post-transplantation. Un apport particulièrement significatif de l'analyse et de l'interprétation de nos données est la mise en relief que le processus de transplantation est mieux compris lorsque l'on considère le contexte social et interpersonnel plus large dans lequel évolue chaque dyade donneur-receveur, et en ce sens, la décision de donner ou d'accepter un rein peut être appréhendée comme un prolongement du rôle social auquel la personne adhère par rapport à autrui dans sa vie quotidienne.

Le troisième article, qui a émergé des leçons acquises en réalisant la recherche effectuée dans l'article précédent, vise à décrire et discuter des défis éthiques et des impacts des décisions méthodologiques dans le cadre de recherches qualitatives impliquant des dyades de personnes se connaissant. Sur la base de nos propres défis empiriques et des écrits scientifiques disponibles, des réflexions et recommandations sont suggérées à différents stades d'un processus typique de recherche qualitative, soit (a) le recrutement, (b) le consentement à participer, (c) la collecte de données, (d) la validation des transcriptions par les participants, (e) l'analyse de données, et (f) la dissémination des résultats. Une réflexion en amont des enjeux entourant ces étapes est susceptible de faciliter l'entreprise de recherches qualitatives impliquant des dyades.

En conclusion, les résultats de notre analyse soulignent l'importance du rôle social et du contexte interpersonnel plus large dans lequel évoluent les donneurs et les receveurs dans la façon dont ils parviennent à donner une signification à leur expérience. Enfin, si la recherche qualitative impliquant des dyades est en émergence, des défis éthiques et des décisions méthodologiques rigoureuses doivent être considérés en amont.

Mots clés: Transplantation d'organe, donation vivante de rein, méta-résumé, analyse phénoménologique interprétative, rôles sociaux, don, altruisme, enjeux éthiques et méthodologiques, confidentialité, dyades.

ABSTRACT

The global objective of this thesis is to help develop a better understanding of how living kidney transplantation donors and recipients experience the donation process as an interactive dyad. To address this objective, we suggest an in-depth exploration of the transplant trajectory and of the relational issues at play between donors and recipients in the context of a living kidney donation. A secondary objective, which developed along the way, is to contribute to a better understanding of how to conduct qualitative research with dyads.

This thesis is comprised of three articles. The first article is a meta-summary that aimed at aggregating results pertaining to both donors and recipients of a living kidney donation to offer a complete picture of the donation process and to highlight avenues that warrant further research, namely looking at both donors and recipients as an interactive dyad within the same study.

The objective of the second article was to provide a better understanding of how living kidney transplantation donors and recipients experience the donation process as an interactive dyad, and in particular the transplant trajectory and the relational issues involved. In-depth qualitative interviews were conducted with five dyads (five donors and five recipients). An interpretative phenomenological analysis of the data suggests that the transplant process can be naturally broken down into five phases of the transplant process: (a) the experience of the disease, (b) the experience of offering and accepting a kidney, (c) the screening period, (d) the surgery, and (e) the post-transplantation period. We found that for each donor-recipient dyad, the transplantation process reflects the unique larger social and interpersonal context within which the dyad evolves, and in this sense, the decision to donate or accept a kidney becomes a reflection of the social role one adheres to with respect to another being in everyday life.

The third article emerged from the lessons we learned in conducting the research described in the second article and describes both the ethical challenges and methodological decisions involved in conducting qualitative research with dyads who have shared a common experience. Based on our experience and on the available literature, we offer reflections and recommendations that follow the typical chronology of the research process: (a) recruitment, (b) consent to participation, (c) data collection, (d) transcript validation by participants, (e) data analysis, and (f) result dissemination. Reflecting ahead upon issues at each of these stages is likely to be beneficial in conducting rigorous qualitative research involving dyads.

In conclusion, our results underline the importance of the unique larger social and interpersonal context within which dyads evolve and achieve a sense of meaning with respect to their own experience of the donation process. Last, as qualitative research involving dyads continues to evolve, ethical challenges and rigorous methodological decisions should be reflected upon ahead of time.

Keywords: Organ transplantation, living kidney donation, meta-summary, interpretative phenomenological analysis, social roles, gift, altruism, ethical and methodological issues, confidentiality, dyads.

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Introduction générale

APA	American Psychological Association
DVR	donation vivante de rein
IPA	analyse phénoménologique interprétative
IRCT	inuffisance rénale chronique terminale

First article

CIHI	Canadian Institute for Health Information
UNOS	United Network for Organ Sharing

Second article

CIHI	Canadian Institute for Health Information
LKT	Living kidney transplantation
IPA	interpretative phenomenological analysis
OPTN	Organ Procurement and Transplantation Network

Discussion générale

DVR	donation vivante de rein
IPA	analyse phénoménologique interprétative

À toi qui vient bouleverser ma vie…

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C’est pleine d’émotions parodoxales que je jette un dernier regard sur ma vie de doctorante, avant de m’engager pleinement dans ma vie de professionnelle et de jeune maman. Mes années de doctorat ont été riches en activités variées et en rencontres qui m’ont transformée, et j’en ressors assurément grandie et épanouie. Toutefois, je vis aussi un peu de nostalgie à laisser derrière moi cette belle étape de ma vie.

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AVANT-PROPOS

Les questionnements à l’origine de cette thèse s’inscrivent dans mon intérêt de mieux comprendre l’expérience des personnes qui vivent l’épreuve de la maladie. En effet, la maladie fait souvent l’effet de l’orage dans un ciel clair, déchirant la vie entre un "avant" et un "après", et modifie de façon susbtantielle la réalité quotidienne. En comprenant mieux ce par quoi passent les personnes atteintes de maladie, il devient alors possible selon moi de mieux les accompagner.

Bien qu’aucune expérience individuelle ne puisse expliquer de façon évidente la source des questionnements de cette thèse, les réflexions théoriques et cliniques sur la santé et la maladie me passionnent depuis la réalisation de ma maîtrise en psychologie de la santé à l’Université de Lausanne. Chacun des choix théoriques, conceptuels et méthodologiques découlent de connaissances et de réflexions intellectuelles, mais également de mes valeurs et de mes croyances par rapport à l’individu, et de ma conception du rôle de chercheur en psychologie.

CHAPITRE 1

INTRODUCTION GÉNÉRALE

"Cette greffe devient alors notre greffe, notre action partagée contre le coup du sort. Je réponds oui à ce qui nous permet de prendre à bras-le-corps notre épreuve commune – changement drastique de notre vie – pour construire une issue positive. Alors, gratitude envers son geste ? Oui, bien sûr, mais dans une relation égalitaire. Je ne suis pas écrasée par cette offre, chacun de nous fait ce qu'il peut pour résoudre cet aléa de la vie qui nous accable. Il me dit : "La gratitude, c'est que ça marche.""

- Christian et Olga Baudelot, (2008), p. 194-195 -

Encore de nos jours, la transplantation d'organes fascine et constitue un univers plein d'imaginaires. Ce procédé médical consistant à prélever un organe au sein d'un individu, pour le greffer ensuite chez un autre, amène son lot de défis, de prouesses techniques et d'enjeux éthiques et culturels. Comme l'aborde notamment Le Breton (2008), un enjeu particulier de la transplantation d'organe réside dans le rapport que nous entretenons avec le corps, et, en particulier, avec le cadavre humain. En effet, pour réaliser une transplantation d'organe, il s'agit de prélever un organe dans le corps d'une autre personne, vivante ou décédée. Dès le début du XX$^{\text{ème}}$ siècle, plusieurs chirurgiens à travers le monde ont tenté d'effectuer des transplantations d'organe, que ce soit à partir de donneurs animaux, décédés ou de jumeaux identiques. Les résultats seront mitigés, jusqu'à ce que la médication immunosuppressive (cyclosporine par exemple) soit significativement améliorée dans les années 1980 (Le Breton, 2008), permettant ainsi que le greffon ne soit plus rejeté par le système immunitaire de son nouvel hôte.

Actuellement, les transplantations d'organe constituent une pratique médicale routinière, et l'opération chirurgicale d'introduction d'un greffon dans le corps d'un receveur est devenue presque banale. La transplantation rénale constitue d'ailleurs le traitement de suppléance unanimement recommandé en cas d'insuffisance rénale chronique terminale (IRCT)[1] (Jungers, Man, & Legendre, 2004; Knoll, 2008), puisqu'elle permet au receveur de bénéficier d'une meilleure qualité de vie et d'un prolongement de son espérance de vie (Dew et al., 1997) et qu'elle est économiquement plus rentable que la dialyse[2] (Azar et al., 2007). La dialyse est en effet considérée comme un traitement de suppléance médicalement moins efficace que la transplantation rénale (Jungers et al., 2004), et est également vécue de façon très contraignante par les personnes concernées (Orr, Willis, Holmes, Britton, & Orr, 2007). La transplantation rénale peut être réalisée à partir de greffons rénaux provenant de personnes décédées, mais il est également possible d'effectuer une donation vivante de rein (DVR), soit transplanter le greffon rénal prélevé auprès d'un donneur vivant partageant une certaine compatibilité sanguine et immunologique avec le receveur. Dans le cas d'une DVR, il faut d'abord s'assurer de l'histocompatibilité[3], et ce pour deux raisons importantes. En premier lieu, les antigènes des leucocytes humains (communément appelés HLA pour *human leukocyte antigen*) jouent un rôle central dans la réponse immunitaire, qui déterminera en grande partie le résultat de la transplantation. En second lieu, l'important polymorphisme des antigènes des leucocytes humains peut constituer un obs-

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[1] L'IRCT est caractérisée par la perte définitive de la fonction rénale.

[2] La dialyse est un «procédé thérapeutique temporaire ou définitif, permettant d'éliminer les toxines (urée, acide urique) et l'eau qui sont contenues en trop grande quantité dans le sang lorsque les reins ne sont plus en mesure d'assurer leur fonction de maintien de l'organisme dans un équilibre en eau, sodium, potassium et calcium aussi parfait que possible» (Institut national d'excellence en santé et en services sociaux [INESSS], 2012, p. xix).

[3] Le taux de compatibilité entre deux tissus ou deux organes qui permet à une greffe de ne pas être rejetée.

tacle majeur au succès d'une transplantation, c'est la raison pour laquelle leur correspondance, la meilleure compréhension de leur fonctionnement, ainsi que l'amélioration des traitements d'immunosuppression, ont contribué à une meilleure planification des DVR et à de meilleurs résultats (Takemoto, Port, Claas, & Duquesnoy, 2004). En effet, la DVR comporte plusieurs avantages par rapport à la transplantation rénale cadavérique, notamment une meilleure planification de l'intervention chirurgicale, permettant ainsi de diminuer, voire éviter le temps passé en dialyse (Glannon, 2008), un greffon rénal de qualité supérieure, ainsi qu'une longévité du greffon plus favorable (Crombie, 2006)[4]. Enfin, étant donné la pénurie de greffons rénaux provenant de source cadavérique et le nombre de personnes actuellement en attente pour un greffon rénal au Québec, au Canada et dans la plupart des sociétés industrialisées, la DVR constitue une pratique de plus en plus courante dans de nombreux centres de transplantation (Institut canadien d'information sur la santé [ICIS], 2012).

Parallèlement à ces avantages et progrès biomédicaux, la DVR a également été considérée sous un angle éthique. En effet, la question se posait de savoir si la pratique d'opérer une personne en bonne santé pour lui retirer un rein et le greffer chez un autre individu atteint d'IRCT était éthique et adéquate (Quante & Wiedebusch, 2007). C'est pour cette raison que les premières recherches effectuées sur la problématique ont porté sur différents aspects inhérents à la santé des donneurs vivants à court, moyen et long terme, ainsi qu'à leur bien-être et leur qualité de vie après l'intervention chirurgicale de néphrectomie laparoscopique[5]. Il en ressort que cette intervention chirurgicale est considérée comme une procédure à faible risque pour la santé du donneur (El-Agroudy et al., 2007; Wright, Faith, Richardson, & Grant, 2004), comportant un

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[4] Si un greffon rénal d'origine cadavérique possède une demi-vie d'environ 8 ans, celle d'un greffon issu de DVR peut atteindre entre 12 et 26 ans.

[5] Retrait du rein par voie endoscopique, soit au moyen d'un instrument composé d'un tube.

risque de mortalité péri-opératoire de 0,03 % (Najarian, Chavers, McHugh, & Matas, 1992), que le don de rein ne détériore pas la fonction rénale (Najarian et al., 1992), que l'espérance de vie n'est pas réduite (Ramcharan & Matas, 2002) et que le degré de santé est au moins aussi élevé que celui de la population générale (Fehrman-Ekholm et al., 2000). Ainsi, si la majorité des auteurs conclut que la pratique de DVR peut être considérée comme éthique, pour autant que le donneur puisse donner un consentement libre et éclairé, soit disposer d'une réelle liberté de choix de son acte et une pleine connaissances des risques et complications éventuelles ainsi que des bénéfices attendus (Siebels et al., 2003; Wright et al., 2004), d'autres (notamment Glannon, 2008) plaident pour la mise sur pied de critères de sélection encore plus rigoureux dans l'examen des donneurs vivants potentiels (Danovitch, Hou, & Levey, 2012; Duerinckx et al., 2014; The Authors for the Live Organ Donor Consensus Group, 2000; Tong, Chapman, Wong, de Bruijn, & Craig, 2011) ainsi que l'instauration d'un suivi médical systématique post-opératoire pour les donneurs vivants (McCune et al., 2004), notamment à cause d'éventuelles complications sur le long terme, et de l'apparition d'anciens donneurs vivants sur des listes d'attente pour un greffon rénal.

1.1 Donneur-receveur : une dyade en interaction

Lorsque l'on considère la DVR, il est important de concevoir le donneur et le receveur comme une dyade en interaction (Baines & Jindal, 2003), et ce même si les études portant conjointement sur les donneurs et les receveurs, permettant ainsi de mieux comprendre la globalité et la complexité de ce processus, sont encore largement absentes des écrits empiriques actuels (Sajjad, Baines, Salifu, & Jindal, 2007). D'un point de vue clinique, des questionnements relatifs à la relation entre le donneur et le receveur ont quelques fois été relevés dans le cadre de l'évaluation multidisciplinaire des donneurs et des receveurs. Les directives canadiennes en la matière recommandent par ailleurs de réaliser l'évaluation du donneur et celle du receveur par deux équipes soignantes distinctes, de manière à bien comprendre la perspective des deux parties impliquées et de s'assurer qu'il n'y ait pas d'enjeux de pouvoir entre le donneur et le receveur (Wright et al., 2004).

Outre cet aspect, au Québec, la DVR se fait majoritairement dans le cadre de dyades donneur-receveur qui se connaissent et qui entretiennent des liens familiaux et/ou émotionnels, puisque les cas de donation altruiste sont encore extrêmement marginaux en transplantation rénale à ce jour. À cet égard, la relation entretenue par le donneur et le receveur avant, pendant et après la DVR est particulièrement importante, tout comme le rôle social et familial que joue par ailleurs chacun des protagonistes, comme nous y reviendrons plus loin dans l'introduction. Parmi les enjeux relationnels particuliers que l'on peut retrouver au sein d'une dyade donneur-receveur, on peut retrouver la pression, conflictuelle, situationnelle et/ou subtile parfois relevée (Conrad & Murray, 1999), les enjeux de prise de décision de donneur et du receveur, dans un contexte relationnel particulier, où la prise de décision de l'un influence obligatoirement la prise de décision de l'autre, la possibilité pour le receveur de se sentir redevable et endetté par rapport au donneur (Crombie & Franklin, 2006), et donc l'évolution de la relation entre le donneur et le receveur après la transplantation. Une étude allemande a mis en évidence de la détresse psychologique au sein de plusieurs dyades donneur-receveur, avec des problèmes tels qu'une escalade des conflits conjugaux après la transplantation, la non-compliance du receveur suite à une impasse conjugale ainsi que des conflits familiaux chroniques suite à un refus de donner (Greif-Higer, Wandel, Otto, Galle, & Beutel, 2008). L'étude psychologique de la DVR se doit donc de considérer les aspects psychologiques, émotionnels et relationnels en jeu au sein de la dyade donneur-receveur.

1.2 Don d'organe, altruisme et théorie du don

Les théories de l'altruisme et de l'égoïsme ont été largement débattues dans les écrits scientifiques, que ce soit au sein de disciplines comme la philosophie, l'économie, la psychologie sociale ou la biologie sociale, et aucun consensus n'a été atteint relativement à la compréhension de la motivation à aider autrui (Sharp & Randhawa, 2014). Après leur révision des écrits, Sharp et Randhawa (2014) concluent que l'altruisme constitue une partie significative de la motivation sous-tendant la donation d'organe, mais que ce concept comporte des composantes sociales et culturelles, et qu'il ne s'applique pas de façon universelle. Ils proposent que les éléments d'échange et de réciprocité de la théorie du don permettent un éclairage plus complet et plus approprié de la problématique de la donation d'organes. En effet, dès les débuts de la transplantation d'organe, notamment de source cadavérique, les législateurs et les décideurs ont parlé de "don de vie", d'un cadeau offert dans une perspective altruiste ou encore d'un cadeau inestimable (Gerrand, 1994). En présentant l'acte de la sorte, on pensait encourager le volontarisme et l'altruisme en donation d'organe. Les recherches en transplantation qui s'intéressent à cet aspect se réfèrent fréquemment à la théorie du don de l'anthropologue Marcel Maus (1950/2012). Cet auteur présente un système du don caractérisé par trois obligations interreliées : l'obligation de donner, l'obligation de recevoir et l'obligation de rendre, trois moments qu'il dégage à la suite de son analyse des systèmes d'échange en vigueur dans les sociétés polynésiennes. Ainsi, l'obligation de donner fait référence à une absence de choix : il faut un premier don afin qu'un échange relationnel puisse être initié. L'obligation de recevoir se comprend intuitivement : refuser un don serait alors refuser la relation, laissant ainsi émerger chez le donneur des sentiments d'humiliation et d'hostilité envers le receveur. L'obligation de rendre est plus complexe puisqu'un retour du don est fondamentalement antinomique. Pour Mauss, cela s'effectue par la notion de *hau*, l'esprit de la chose donnée, qui n'est autre qu'une parcelle de l'esprit du donneur, et qui devra, d'une manière ou d'une autre, faire un retour à son propriétaire. Ainsi, remerciement, gratitude, contre-don constituent des formes, parmi d'autres, d'un retour dont la caractéristique est de ne jamais être totalement garanti, ni surtout immédiat. L'obligation de rendre permet au cercle du don d'évoluer vers une spirale du don, qui, par définition, n'est jamais clôturée, et donc à l'opposé d'un échange marchand. En somme, l'obligation de rendre se confond avec la première obligation, celle de donner, puisque donner selon Mauss, c'est rendre, dans un même mouvement (Schwering, 2014).

Pour certains auteurs, le problème de cette métaphore du don dans un contexte de transplantation d'organe est l'enjeu de réciprocité (O'Brien, Donaghue, Walker, & Wood, 2014), surtout dans le cas de greffons cadavériques, puisque le donneur étant décédé, le receveur ne peut directement rendre sa "dette" à son destinataire. Pour d'autres auteurs, c'est son caractère trop ambigu qui est critiqué (Shaw, 2010) ; en effet, s'il peut s'avérer utile pour sensibiliser l'opinion publique à la problématique de la donation d'organe, il s'est avéré un contexte théorique peu adéquat pour conceptualiser ce à quoi fait face une famille au chevet d'un mourant pour prendre une décision de don d'organe (Sque, Payne, & Clark, 2006). Pour Schwering, (2014), au contraire, si le retour du don peut être le retour d'une autre chose, autrement, et même à quelqu'un d'autre, comme dans un acte de bénévolat, le cadre de la théorie du don, et surtout la perspective de la spirale du don, peut s'avérer appropriée. Dans le cas de la DVR, moins d'auteurs ont abordé la théorie du don, même si le degré de similarité semble plus important, puisque dans le cas de la DVR, le don "appartient" au donneur, et qu'il y a une relation préétablie entre le donneur et le receveur (Gill & Lowes, 2008). Il a également été proposé que des membres de la famille d'une personne atteinte d'IRCT pouvaient se sentir forcés de donner un rein pour aider leur proche à retrouver la santé, et que le receveur pouvait se sentir obligé d'accepter l'offre, puisqu'un refus pourrait signifier le rejet du donneur ou de leur relation. Enfin, le rendre pourrait constituer un défi lorsque le don est d'une valeur telle qu'est un organe (Fortin, Dion-Labrie, Hébert, & Doucet, 2010). Pour Sharp et Randhawa (2014), l'avantage de la théorie du don en contexte de DVR est qu'il permet de considérer la perspective du receveur à travers l'obligation de recevoir, ainsi que les enjeux de réciprocité. C'est en partie la raison pour laquelle la théorie du don constitue une perspective théorique pour l'interprétation des données empiriques de la présente thèse.

1.3 Perspective plus large : les rôles sociaux et familiaux

Dans un contexte de donation vivante de foie, Erim et al. (2012) ont suggéré qu'outre la relation entre le donneur et le receveur, le rôle social joué par chacun des membres de la dyade était important, et que le type de relation familiale peut avoir une influence importante sur le fardeau mental perçu et sur la qualité de vie émotionnelle. Par exemple, lorsque des parents donnaient un foie à un enfant, ils avaient des scores de dépression et d'anxiété plus faibles que des enfants adultes ayant fait un don à un parent. Ces résultats empiriques suggèrent de concevoir l'expérience et le sens que peut prendre l'expérience de donner et de recevoir en contexte de donation vivante d'organe en considérant de façon plus large le rôle social et familial de chacun des membres de la dyade, de même que le contexte interpersonnel dans lequel évolue chaque dyade. C'est également la conclusion à laquelle nous sommes arrivés lors de l'analyse de nos données empiriques qui prenaient une signification nouvelle lorsqu'appréhendées selon la perspective du rôle social tel que décrit en psychologie sociale. En ce sens, la réalisation d'un rôle social a été associée à trois besoins psychologiques : l'autonomie, le fait d'être en lien avec autrui[6] et la compétence (Bettencourt, Molix, Talley, & Sheldon, 2006; Talley, Kocum, Schlegel, Molix, & Bettencourt, 2012). Cette perspective théorique inspirée de la psychologie sociale constituera un deuxième angle d'interprétation de nos données empiriques.

1.4 Recherche qualitative avec des dyades : enjeux éthiques et méthodologiques

Enfin, le choix méthodologique de récolter des données empiriques qualitatives auprès de dyades donneur-receveur a amené son lot de défis dans la réalisation de la présente thèse ; en particulier lorsque la publication des résultats des analyses dyadiques (et notamment de verbatims issus des entrevues de recherche) pouvait mettre en péril la protection de la vie privée et la confidentialité engagée auprès des participants de recherche. Cette tension entre la rigueur méthodologique (accéder à des données détaillées et de qualité), la dissémination suffisamment complète des résultats et la responsabilité éthique (respecter l'engagement de confidentialité auprès des participants) a stimulé la réflexion sur les différents enjeux inhérents à la réalisation de recherches qualitatives impliquant des personnes se connaissant et partageant une expérience commune. Cette réflexion, initiée par une embûche rencontrée sur le terrain, est étayée par les

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[6] Traduction personnelle de l'original anglais *relatedness*.

quelques écrits disponibles sur les recherches dyadiques dans le courant qualitatif.

1.5 Objectifs de la présente thèse

La présente thèse vise une contribution à la fois théorique, clinique et méthodologique. Au plan théorique, le premier objectif poursuivi est de tenter de mieux comprendre en quoi consiste l'expérience de donner et de recevoir un rein dans un contexte de DVR. Plus précisément il s'agit :

a. de procéder à une recension systématique des études empiriques qualitatives portant sur l'expérience des donneurs et des receveurs d'une DVR ;

b. d'extraire les résultats obtenus sous la forme de la méthode du métarésumé.

Le deuxième objectif de la présente thèse vise un apport théorique et clinique qui sera atteint par l'analyse de données empiriques. L'objectif est ici de mieux comprendre l'expérience de dyades donneur-receveur en contexte de DVR. Plus précisément, il s'agit de tenter :

a. de mieux comprendre l'expérience de donner et de recevoir un rein en contexte de DVR ;

b. de décrire les moments clés du parcours de transplantation ;

c. d'explorer les enjeux dyadiques relationnels plus larges, notamment les rôles sociaux.

Le troisième objectif poursuivi par la présente thèse propose une contribution sur les plans théorique et méthodologique. Il consiste en la discussion des enjeux éthiques et de respect de la confidentialité entourant la recherche qualitative impliquant plusieurs personnes se connaissant et partageant une expérience commune. Il s'agit notamment :

a. d'étayer les obstables rencontrés dans le processus empirique par la consultation des écrits disponibles sur le sujet ;

b. de proposer des suggestions, recommandations et pistes de réflexion pour les différentes étapes d'un processus de recherche ;

c. de contribuer à l'essor d'une pratique rigoureuse et avertie de la recherche qualitative impliquant des dyades.

1.6 Structure de la thèse

Le prochain chapitre (deuxième chapitre) comprend un article publié en 2011 dans le périodique *Journal of Transplantation*, à savoir un métarésumé portant sur l'expérience des donneurs et des receveurs d'une DVR. Ce premier article permet de répondre aux deux premiers objectifs mentionnés ci-dessus.

Le chapitre subséquent (troisième chapitre) comprend un article publié en 2015 dans le périodique *Qualitative Health Research*. Cet article empirique propose une réponse à la deuxième série d'objectifs et présente un apport théorique accompagné de recommandations pour la pratique clinique issu de données empiriques qualitatives récoltées et analysées dans la tradition de l'analyse phénoménologique interprétative (IPA).

Le quatrième chapitre comprend un article méthodologique et théorique qui se propose de répondre à la troisième série d'objectifs. Cet article a été soumis le 8 juin 2015 au périodique *Qualitative Health Research*.

En dernier lieu, le cinquième chapitre est constitué d'une discussion générale qui reprend l'essentiel des conclusions tirées des articles présentés dans les chapitres précédents. Il présente ainsi une synthèse quant à la contribution de la présente thèse, tant au niveau scientifique que clinique. Il aborde également une appréciation des limites de la présente thèse, ainsi que de possibles implications pour des recherches futures.

1.7 Contribution des co-auteurs

Pour chacun des articles présentés dans le cadre de la présente thèse, l'ordre des auteurs correspond à leur contribution respective en fonction des normes de publication de l'*American Psychological Association* (APA). Ainsi, l'auteure de la thèse a été la contributrice principale de l'ensemble du processus du recherche, de la conceptualisation du devis de recherche à la rédaction des articles. Marie Achille a supervisé le processus de recherche et révisé tous les travaux écrits. Pour le premier article, la sélection des articles, l'extraction des contenus ainsi que leur analyse ont été réalisées en étroite collaboration avec Jessica Mekkelholt. Le manuscrit a été révisé par Marie Achille. Pour le deuxième article, impliquant les données empiriques, l'auteure de la thèse a développé les grilles d'entrevue et conduit les entrevues de recherche auprès des dix participants, vérifié l'exactitude des transcriptions des entrevues et effectué l'analyse des données ainsi que leur interprétation, le tout en collaboration avec Marie Achille, qui a également révisé le manuscrit. Pour le troisième article abordant les aspects éthiques et méthodologiques, l'auteure de la thèse a consulté les écrits disponibles, conceptualisé et rédigé le manuscrit en étroite collaboration avec Marie Achille. Les accords des co-auteurs ainsi que l'avis d'acceptation des éditeurs des périodiques dans lesquels les articles ont été publiés ou soumis ont préalablement été obtenus.

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CHAPITRE 2

FIRST ARTICLE

Donors and Recipients of Living Kidney Donation: A Qualitative Metasummary of Their Experiences

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2.1 Abstract

With the notable growth in the qualitative investigation of living kidney donation, there is value in aggregating results from this body of research to learn from accumulated experience. The present article aims to draw a complete portrait of living donors' and recipients' experience of donation by meta-summarizing published studies. We found that donors' experience, particularly the decision-making process, has been more extensively studied than the recipients' perspective. Donors differ in their initial level of motivation to donate but on the whole report positive experiences and personal benefits. They also identify difficult periods and the need for additional resources. Recipients report an often positive but more ambivalent reaction to donation. In terms of relational issues between dyads, while the topic remains understudied, the donor-recipient relationship and gift reciprocity have received the most attention. Results are discussed in terms of their implications for future practice and research.

Keywords: living donation, renal or kidney transplantation, psychosocial aspects, qualitative research, metasummary.

2.2 Introduction

Renal transplantation is considered the best treatment in the case of end stage renal disease (Knoll, 2008), as it is associated with better quality of life and a longer life expectancy (Dew et al., 1997), and is more profitable economically (Azar et al., 2007) than dialysis. Given the shortage of renal graft from deceased persons (United Network for Organ Sharing [UNOS], 2009; Canadian Institute for Health Information [CIHI], 2008), the low risk involved for the donor (El-Agroudy et al., 2007; Ibrahim et al., 2009), and the improved quality of life likely to result for the recipient (Binet et al., 1997; Glannon, 2008), living kidney donation is currently being promoted and increasingly practiced in all western societies (Horvat, Shariff, & Garg, 2009).

Living kidney donors have received much research attention for evident ethical reasons (Paramesh et al., 2007), namely to establish the low risk involved and positive long-term effects of living donation. Numerous quantitative studies conclude that donors usually experience their donation act in a positive manner and that they would reiterate their gesture if possible (Achille, Soos, Fortin, Pâquet, & Hébert, 2007; Johnson et al., 1999; Isotani et al., 2002; Ku, 2005; Fehrman-Ekholm et al., 2000; Jowsey & Schneekloth, 2008; Giessing et al., 2004). In terms of their quality of life, donors' scores are higher than reference populations, even after surgery (Johnson et al., 1999; Smith, Trauer, Kerr, & Chadban, 2003). Donors also report personal benefits from their donation experience, such as a higher self-esteem or well-being after donating (Isotani et al., 2002; Achille, Vaillancourt, & Beaulieu-Pelletier, 2008; Rodrigue et al., 2006, 2008). Donors report personal growth (e.g. an increased appreciation for the value of their own life), interpersonal benefits (e.g. an increased respect and admiration by family and friends) and even spiritual benefits (e.g. the donation is seen as a way of honoring a higher spiritual being) (Achille et al., 2008; Rodrigue et al., 2006, 2008). In spite of this overall positive picture, it is important to mention that a small proportion of donors report poor experiences with donation (Johnson et al., 1999), especially when the renal graft did not function as expected for the recipient (Fehrman-Ekholm et al., 2000). Cases of depression, adjustment disorder and anxiety have been reported, even when surgery outcomes were positive for the recipient and without any medical complication for the donor (Smith et al., 2003; Fukunishi et al., 1998).

While quantitative studies give a very valuable but often partial description of a complex process such as living donation, qualitative studies, typically conducted on a smaller scale, allow a complementary in-depth exploration of complex human experiences (Denzin & Lincoln, 2005; Patton, 2002). As mentioned previously (Ummel & Achille, 2011), if living kidney donors have been brightly studied, there is a lack of studies addressing the particular situation of receiving a kidney from a live donor. In the present study, we are aggregating results pertaining to the experience of both donors and recipients of a living kidney donation in order to offer a complete picture of the donation process as it has been examined thus far in the empirical literature. Summarizing these qualitative results will add to the transplantation community's continuing clinical and research efforts to understand the accumulated experience of living donation. This seems particularly timely in the current context of the active promotion of living donation and access to novel donation avenues (e.g. paired exchange).

The present article focuses uniquely on living kidney donation, as other forms of living donations (e.g., liver, partial lung) are performed in very different contexts in terms of the urgency with which decisions have to be made, the risks involved for the donors, and the limited alternative options available to intended recipients.

2.3 Materials and Methods

2.3.1 Selection criteria

We included qualitative studies that used interviews or focus groups to explore donors' and recipients' experience of living kidney donation. We included solely studies published in peer-reviewed journals and written in English, French or German, so that we could understand them completely. We excluded studies that reported only quantitative data or used structured questionnaire as their only method for data collection.

2.3.2 Article Retrieval

In November 2010, we conducted a literature search in three databases: PsycINFO (1987 to November Week 1 2010), CINAHL and Medline (1996 to October Week 4 2010). In PsycINFO, we obtained 75 results with the use of the keyword "living don*" (*denotes truncation), in CINAHL we obtained 100 results by using "living don* AND renal or kidney" and in Medline, we obtained 79 results combining the following keywords: "living don* AND kidney or renal AND qualitative or focus group* or interview* or case stud*". After removing articles that appeared in more than one database, we ended up with 236 articles and examined their title, abstract and eventually the entire study to select those meeting our selection criteria. To confirm no omission of relevant articles, we scrutinized reference lists of literature reviews (Morton, Tong, Howard, Snelling, & Webster, 2010; Lukasczik, Neuderth, Kohn, & Faller, 2008) and of the 15 articles selected for this review (see Table 2.1).

2.3.3 Synthesis of findings

The 15 articles were meta-summarized following techniques described by Sandelowski and Barroso (2003b, 2003a). The articles were reviewed and relevant findings were extracted from each study included in the review. We then grouped the findings in common topical domains and summarized them into abstracted findings (Table 2.2) (Sandelowski & Barroso, 2007). Subsequently, we calculated *frequency effect sizes of findings* and *intensity effect sizes of studies*, considering each study as one unit of analysis and weighting each study equally (Sandelowski & Barroso, 2003b; Onwuegbuzie, 2003). The *intensity effect size of studies* was calculated by dividing the number of findings of each study by the total number of findings extracted through our meta-summary (54). The *frequency effect size of findings* was calculated by dividing the number of studies mentioning a particular finding by the total number of studies included in our meta-summary (15). The synthesis of findings is shown in Table 2.2, with a frequency effect size reported for each finding (e.g. altruistic and natural decision's frequency effect size is 46.7% because this finding appeared in 7 of 15 studies) and an intensity effect size reported for each study (e.g. (Gill & Lowes, 2008) has a 33.3% intensity effect size, because it contains 18 findings out of total 54 reported in the present metasummary).

2.4 Results

Results are presented following the typical chronology of the living kidney donation process, namely results pertaining to the decision-making phase are presented first, followed by those pertaining to the timing of donation, then by those relevant to the period after donation. We begin with the donors' experience, as it has been more extensively investigated in the current literature.

We next present the literature on recipients, and finally address relational issues between donors and recipients. A schematic representation of the results is provided in Figure 2.1. Figure 2.1 also illustrates that donor issues have been studied more in depth than relational or recipients' issues. Detailed results are presented in Table 2.2.

2.4.1 Donors

2.4.1.1 Decision-making process

The donors' decision-making process usually starts with a deliberation phase where donors begin having thoughts about giving a kidney to a recipient. This typically happens before the decision to be tested for compatibility (Yi, 2003). Donors' decision-making process appears to be influenced by several factors that differ from one donor to the other. Awareness of recipient's suffering appeared to be a consensual and powerful motivation and an influential factor in donors' decision (Gill & Lowes, 2008; Brown et al., 2008a, 2008b; Crombie & Franklin, 2006; Haljamäe, Nyberg, & Sjöström, 2003; Heck, Schweitzer, & Seidel-Wiesel, 2004; Sanner, 2005; Waterman et al., 2006). For some donors, it was an altruistic and natural decision meant to improve the recipient's health and quality of life (Gill & Lowes, 2008; Yi, 2003; Brown et al., 2008a; Haljamäe et al., 2003; Waterman et al., 2006; Andersen et al., 2005; Walsh, 2004) but this decision could also be more philosophical or spiritual in nature (Yi, 2003; Brown et al., 2008a; Walsh, 2004). Some studies described donors' decision as carefully thought through (Yi, 2003; Brown et al., 2008a, 2008b; Sanner, 2005; Andersen et al., 2005; Walsh, 2004), whereas other stated it was a quick and straightforward decision (Gill & Lowes, 2008; Sanner, 2005). In addition, the decision was also often described as sufficiently informed and rational (Gill &

Lowes, 2008; Brown et al., 2008b; Haljamäe et al., 2003; Sanner, 2005).

Numerous studies highlight familial issues, but no clear consensus from these different studies emerged in terms of how certain types of relationships (e.g. siblings, parent-child) impacted decision-making or outcome. Within families where more than one potential donor was available, there was often mediation and negotiation in order to find the best family member to assume this role (Crombie & Franklin, 2006). It seems that the reason expressed to become a donor could depend on the familial relationship status with the recipient (e.g. being a mother or a brother), but the findings extracted lead to no consensus on this (Gill & Lowes, 2008; Yi, 2003; Brown et al., 2008a; Crombie & Franklin, 2006; Haljamäe et al., 2003; Andersen et al., 2005; Walsh, 2004; Franklin & Crombie, 2003). However, one consensus was found around the absence of pressure from others donors felt in their decision-making process (Gill & Lowes, 2008; Haljamäe et al., 2003; Sanner, 2005; Andersen et al., 2005). One study argued that intimacy with the recipient is an important factor in the decision-making process, and the more intimate the donor and the recipient are, the higher the wish to give (Yi, 2003). Even when wishing to give a kidney, donors often felt anxiety during the process (Sanner, 2005; Walsh, 2004), from the risk of surgery (Brown et al., 2008a) or the stress of being declined as a donor (Brown et al., 2008b) for example.

The timing at which donors made their final decision differed greatly between participants and studies. Timing partly depended again on the familial relationship with the recipient, but not solely (Sanner, 2005; Franklin & Crombie, 2003). One study reported that the medical examination was experienced as a difficult stage, the worst step, because it was long and involved stress over delays and anxiety regarding results (Sanner, 2005). Being reminded of the possibility to withdraw was reported as experienced negatively by participants in two studies. Indeed, after having made the decision to donate, donors found it unimaginable not to proceed (Brown et al., 2008b) and they understood the repeated information that they could withdraw as a doubt about their decision that had to be defended and maintained (Sanner, 2005).

Social support has been described as important during the decision-making process even though results were not unanimous on that subject. Some donors appreciated the support received from family, friends, colleagues and the broader community who endorsed their decision (Brown et al., 2008a; Walsh, 2004). However, in other cases, members of the immediate family were not considered suitable supporters as they were reported as anxious about the surgery (Sanner, 2005). More generally, donors expressed that there is a need for more emotional support, as existential interrogations, such as questions about life and death and the meaning of life, were activated during the donation process (Sanner, 2005).

One single study (Yi, 2003) detailed the execution phase, being the phase where donors finally arrived at their decision. This study proposed a typology of different donor types: the voluntary type, the compromising type and the passive type. Donors of the voluntary type have an intense will to give, their decision-making process is straightforward and they have strong intimacy with their recipient. They are so determined to give that the process of compatibility testing can be stressful because of the fear of being rejected as a donor. On the other hand, donors of the compromising type have a moderate will to give, resulting in a more complicated decision-making process and a passive participation in compatibility tests. These donors volunteer when the test results are positive, feeling that they have no other choice. In addition, most donors of this type receive financial compensation. Donors of the passive type have a low will to give and are reluctant to take compatibility tests. Their intimacy with the recipient is the lowest. All passive donors are persuaded by family members with financial compensation.

2.4.1.2 At the time of donation

The surgical experience of donation was a theme often examined in the articles reviewed. Just before surgery, donors varied in their attitudes regarding surgery. Although some approached it in a calm manner, it was an anxiety provoking event for others, leading authors to suggest that each donor's needs in this period are unique (Brown et al., 2008b). Some donors made preparations in case they were to die, such as writing a will (Sanner, 2005) and the emotional component of their experience increased in the days leading to the operation (Walsh, 2004). After surgery, numerous studies reported that donors had experienced pain (Gill & Lowes, 2008; Brown et al., 2008b; Sanner, 2005; Andersen et al., 2005; Williams, Colefax, O'Driscoll, & Dawson, 2009), nausea (Gill & Lowes, 2008; Andersen et al., 2005), exhaustion (Crombie & Franklin, 2006; Sanner, 2005; Williams et al., 2009; Andersen et al., 2007) and scar problems (Gill & Lowes, 2008). These effects were expressed as more important than expected, and at some points donors felt they had not been well prepared for these effects. Psychological strain was also mentioned in several studies (Brown et al., 2008b; Heck et al., 2004; Sanner, 2005; Williams et al., 2009; Andersen et al., 2007). Insufficient pain relief could lead to psychological symptoms and reduced emotional capacity in some donors (Crombie & Franklin, 2006; Heck et al., 2004; Sanner, 2005; Andersen et al., 2007), they could experience a sense of loss or grief after donation (Brown et al., 2008a) and the fear of rejection was also an important concern (Williams et al., 2009). Regarding the care experience, several studies reported positive experiences (Brown et al., 2008b; Haljamäe et al., 2003; Sanner, 2005; Walsh, 2004), such as care that was trustworthy and honest (Brown et al., 2008b), namely a call from a coordinator some weeks after discharge (Sanner, 2005) and the availability of support from the transplant health care team when needed (Walsh, 2004). There were some negative aspects to their experiences as well, such as a lack of information after discharge (Brown et al., 2008b) and a distressing and uncomfortable experience at the hospital (Crombie & Franklin, 2006). Some donors also felt abandoned and ignored by the staff (Sanner, 2005). One study highlighted that donors would appreciate receiving better psychological care in such critical situations as regressive reactions, pain attacks, and transplant rejection episodes (Sanner, 2005).

2.4.1.3 After donation

Regarding medical follow-up post-donation, one study reported that the majority of donors expressed satisfaction regarding the care received, but that some donors expressed frustration due to unmet expectations from health professionals (Andersen et al., 2007). With their care mostly being left in the hands of their family doctors, another study reported that donors would have welcomed additional contact with the transplantation health care team (Brown et al., 2008b). Donors were reported as having few worries regarding their future health with only one kidney (Heck et al., 2004; Andersen et al., 2005). One study stated that since donation, donors had become proponents of living kidney donation in the community (Brown et al., 2008a). Advices and recommendations to future donors were also discovered. In one study, donors stressed for future donors the importance for them to make the decision personally and free from any pressure (Brown et al., 2008a). Donors in a separate study emphasized that future donors need to be determined and should not start hesitating (Sanner, 2005). A large consensus was found regarding the absence of regret among donors, and the fact that they report they would make the same decision again (Gill & Lowes, 2008; Brown et al., 2008a; Crombie & Franklin, 2006; Heck et al., 2004; Waterman et al., 2006; Franklin & Crombie, 2003). About one year after donation, all donors were generally physically back to normal, in the sense that they had a good recovery and did not feel any different physically (Gill & Lowes, 2008; Williams et al., 2009; Andersen et al., 2007).

2.4.1.4 Overall experience of donating a kidney

In studies looking at the overall donation process, the experience of living kidney donation has been described as complex, multi-faceted, and as including physical, mental and interpersonal challenges (Andersen et al., 2005; Walsh, 2004). One large consensus found among studies was that donors were reported as having experienced benefits (Haljamäe et al., 2003) such as personal growth (Andersen et al., 2005), increased self-esteem (Brown et al., 2008a), a sense of accomplishment and pride (Heck et al., 2004; Waterman et al., 2006; Andersen et al., 2007), immense personal satisfaction (Gill & Lowes, 2008) and a change in their outlook on life (Williams et al., 2009). The donation was also considered a meaningful action, in the sense of having contributed to a better life for another person (Brown et al., 2008a; Andersen et al., 2005, 2007). However, being a donor was also described as an unfamiliar trajectory as it implied for a fit person to be surgically traumatized (Andersen et al., 2005) and it also led to conflicting roles, as the donor was simultaneously a patient, a close relative to the recipient, and a family member, which could lead to a stressful convalescence (Brown et al., 2008b; Crombie

& Franklin, 2006; Andersen et al., 2005, 2007). When transplantation failed, the experience was reported as unexpected and distressing, and donors' responses were described as depression and sorrow, a feeling of emptiness and a loss of strength (Haljamäe et al., 2003; Heck et al., 2004; Andersen et al., 2007). Another study highlighted that there is a particular need for follow-up after discharge when the graft fails (Brown et al., 2008b).

2.4.2 Recipients

2.4.2.1 Before donation

In order to get a kidney from a live donor, some recipients asked the donor directly, whereas others preferred to wait for the donor to volunteer. One study reported that recipients had different ways of asking for a kidney. Some recipients preferred to ask face-to-face, whereas others thought that writing a letter or an email gave the donor the option to think about it before making the decision (Waterman et al., 2006). On the contrary, other recipients were unwilling to introduce the topic, wanting the donor to volunteer and, therefore, had not asked any potential donor (Gill & Lowes, 2008; Waterman et al., 2006). Some recipients felt anxiety about the risks to the donor's health and wellbeing (Gill & Lowes, 2008; Franklin & Crombie, 2003; Sanner, 2003) and a few had misgivings about accepting the offer (Franklin & Crombie, 2003). Other recipients were afraid the donor was just being polite by undergoing compatibility tests (Waterman et al., 2006). In accepting the kidney, intended recipients often asked themselves whether or not they would do the same and donate a kidney to another individual (Crombie & Franklin, 2006), and some believed it would be insulting to the donor-to-be to refuse their extraordinary offer (Sanner, 2003). In addition, some recipients found it fair to accept given they had been ill for a long time (Sanner, 2003), some expressed positive feelings with regard to the decision to undergo transplantation (Heck et al., 2004), and some stated that having a close relationship with the donor was important (Waterman et al., 2006).

2.4.2.2 After donation

Recipients were found to be extremely grateful to the donors for their donation. They all thanked them for their gesture, but many found it uneasy to articulate their gratitude fully (Gill & Lowes, 2008; Franklin & Crombie, 2003). Most recipients had no regrets about transplantation, however adolescent recipients expressed some regrets largely because of the perceived obligation to accept a kidney proposed by a family member (Franklin & Crombie, 2003). The transplantation's impact on the recipient's health was reported as significant both for the recipient's life and for his or her family (Gill & Lowes, 2008). However, some recipients felt psychological strain, such as depressive symptoms or anxiety, and this was reported to happen despite a favorable medical outcome (Heck et al., 2004) and others lived the overall donation experience negatively (Heck et al., 2004).

2.4.3 Relational issues

2.4.3.1 Donor-recipient relationship

Numerous studies reported that after living kidney donation, the relationship between the donor and the recipient remained the same (e.g. close) or sometimes even improved (Gill & Lowes, 2008; Brown et al., 2008a; Heck et al., 2004; Andersen et al., 2005, 2007; Sanner, 2003). However, there were also cases were the relationship deteriorated (Heck et al., 2004;

Franklin & Crombie, 2003). It seems that familial issues played a role in the evolution of the relationship, but there was no consensus in the two studies that mentioned this (Franklin & Crombie, 2003; Sanner, 2003). Finally, donors and recipients were also found not to have any profound discussion about the transplantation 10 months after transplantation. They felt that even if the transplantation changed their lives, they needed to move on to something else (Gill & Lowes, 2008).

2.4.3.2 Gift reciprocity and obligation to repay

Several studies reported that donors had no expectation regarding repayment or gratitude from the recipient (Gill & Lowes, 2008; Andersen et al., 2005; Franklin & Crombie, 2003). However, some recipients perceived an obligation, such as always being grateful (Crombie & Franklin, 2006; Franklin & Crombie, 2003) and becoming extremely cautious about their own health in the fear they would be held responsible in case of rejection (Brown et al., 2008a; Crombie & Franklin, 2006). Some recipients gave a gift to thank their donor, for example through a small ritual on the anniversary of the transplant date (Brown et al., 2008a; Sanner, 2003). The recipient's sense of gratitude had the potential to alter the relationship (Gill & Lowes, 2008; Heck et al., 2004) and it was reported to be sometimes difficult to cope with having received the gift of donation (Sanner, 2003). Some recipients reduced their feeling of indebtedness by stressing that the donor had also gained from the donation or by playing down the significance of the gift (Sanner, 2003).

2.5 Discussion

The present article aimed to aggregate results pertaining to the experience of both donors and recipients of a living kidney donation in order to offer a complete picture of the donation process.

With respect to the donors' perspective, the decision-making process has been most extensively studied and constitutes the most deeply detailed and complete theme of our metasummary. Considering the implications of a live donation-namely experiencing extensive tests, undergoing a surgical intervention selflessly and losing one kidney-the decision-making process is crucial and it is common sense that it was one of the first aspects to be studied (Yi, 2003). In addition, the literature highlights that awareness of recipient's suffering constitutes a consensual motivation to donate as this finding appeared in 53.3% of studies reviewed, meaning that this finding was found in the majority of studies. The degree of intimacy in the relationship with the intended recipient better predicts the decision to donate than simply the type of relationship (e.g., parent, sibling, etc.). A decision described as altruistic, seen as natural and meant to improve recipient's health also had a very high frequency effect size as this finding emerged in 46.7% of the studies reviewed. This type of decision is also seen in many clinical situations.

Our metasummary further highlights the overall experience of donors, who report having no regret. It is worth noting that the two findings "donors would reiterate their gesture" and "having personally benefited from this process" are findings with very high frequency effect sizes. Forty percent of the reviewed studies indicate that donors would reiterate their gesture and 53.3% of them report personal benefits for donors. This is also consistent with results from quantitative studies previously cited (Achille et al., 2007; Johnson et al., 1999; Isotani et al., 2002; Ku, 2005; Fehrman-Ekholm et al., 2000; Jowsey & Schneekloth, 2008; Giessing et al., 2004), and thus strengthens this common aspect of donors' experience.

Reviewed studies, however, also confirm there are challenging aspects to the donation process. Surgical effects were often more important than expected for donors, and some felt they had not been adequately prepared. Experience of pain, nausea and exhaustion were reported among 46.7% of the reviewed studies. The overall trajectory of donation was described as an experience unlike any other and somewhat unfamiliar; the multiple roles it involved were sometimes a source of strain. In addition, when transplantation outcomes were negative for the recipient, there was an increased risk of emotional and psychological difficulties for donors.

For recipients of a live donation, the experience had many positive aspects but also involved ambivalence to the situation. Candidates for transplantation vary greatly in their willingness to ask their family and friends for a kidney or even introduce the topic. When a kidney is offered, acceptance is preceded by a reflexive process that is concluded with some form of justification for accepting, which is different for each recipient. After donation, recipients experience significant health improvement and are on the whole very grateful to their donor. There is, however, a risk for psychological strain in the context of certain types of relationships between donor and recipient or due to the constraints of the transplantation process (e.g. medical adherence post-transplantation).

In terms or relational issues, our metasummary highlights that the donor-recipient relationship often remains the same, improves or becomes closer, a finding extracted in 40% of studies reviewed. There is, however, also evidence of a risk of deterioration in cases of conflict between donor and recipient, problems and strain related to the transplantation or a relationship already difficult before the transplantation, a finding which was only found among 13.3% of studies reviewed. The issue of gift reciprocity and obligation to repay was also mentioned as having the potential to alter the relationship.

These results suggest avenues to strengthen clinical practice. However, we recognize that practices can likely vary across centers due, in part, to varying degrees of professionals' experience with live donation and availability of resources. Improvements suggested by donors include better preparation for the post-surgical period, easily accessible psychological support throughout the process but also during this particular period, and continued follow-up by the transplantation health care team following donation. Access to psychological support has also been advocated in prior studies (Brown et al., 2008b). In light of donors' discourse on personal benefits of donation and active advocacy following donation, these aspects are important to acknowledge, and should also be shared with potential donors and intended recipients at the outset of the process. Indeed, ethical decision-making involves informing donors about all risks and complications that may occur, but also about potential benefits of the transplant for both recipients and donors.

For recipients, one of the most sensitive and challenging aspects remains informing others about the possibility of donating and the advantages of living kidney donation. This is where transplantation health care teams may be called upon to play a more active role in informing the community of potential donors about this option. How and to whom this publicity may be directed, however, is to be discussed within the boundaries of professional and ethical responsibility. After donation, recipients' discourse suggests a need for increased attention to possible psychological strain, and how to optimize coping with issues of gratitude and reciprocity.

Implications for research are many. For one, recipients' experience of a live kidney donation has received little research attention. Indeed, only one single study explored recipients' experience (Sanner, 2003) and five studies out of 15 addressed some aspects of it (Gill & Lowes, 2008; Crombie & Franklin, 2006; Heck et al., 2004; Waterman et al., 2006; Franklin & Crombie, 2003). In comparison, the donors' perspective was the focus of nine out of 15 studies (Yi, 2003; Brown et al., 2008a, 2008b; Haljamäe et al., 2003; Sanner, 2005; Andersen et al., 2005; Walsh, 2004; Williams et al., 2009; Andersen et al., 2007). In light of this and of available results suggesting that experience of receiving a kidney from a live donor is complex and different from the experience of receiving a kidney from a deceased donor, additional research is needed to investigate the perspective of recipients and donor-recipient dyads. Relational issues in the context of living donation and after transplantation also have received little research attention and, in order to be able to intervene adequately with donors and recipients experiencing relation problems, there is a need to further investigate this area.

It is interesting to note that studies included in the present metasummary emerged from diverse social and cultural contexts, ranging from known-to-be egalitarian societies such as Sweden (Haljamäe et al., 2003; Sanner, 2005, 2003) to highly hierarchical ones such as Korea (Yi, 2003). In this regard, caution is advised in drawing early conclusions on the basis of our metasummary. Also, given the diversity in the findings emerging from these different contexts, there is ground to explore in more detail the impact of social and cultural factors particularly on the decision-making process and on the psychosocial outcomes of transplantation involving live donation.

Although achieved rigorously and systematically, this metasummary has several limitations.

First, we restricted our searches to peer-reviewed journals published in English, French and German, thus eliminating the possibility to include research conducted in theses and dissertations. Secondly, studies retrieved focused on different issues and groups, varying from donors only, to donors and recipients, to recipients only. Even if this highlights the fact that some aspects are still understudied (e.g. the recipients' experience), this could potentially lead to a snap judgement. However, this work offers a complete, empirically-documented overview of donors' and recipients' experience of the donation process.

2.6 Conclusions

A major strength of this work is to offer a complete picture of donors' and recipients' experience of the donation process based on empirical published literature with a rigorous and systematical metasummary technique. These results could be especially useful for new professionals working in the living kidney transplantation field, as well as professionals intervening solely at one particular step of the process. Health care professionals can also gain a certain knowledge about their impact in the process. At a time where there is an active promotion of living kidney donation and access to novel donation avenues, such as paired exchange, it is particularly important to have a better understanding of donors' and recipients' experience of this process.

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2.7 Table 2.1 Characteristics of studies included in the metasummary

Table 2.1: Characteristics of studies included in the metasummary

Reference	Research design / Methodology	Sample	Study purpose / research question as reported by authors	Country
Yi, 2003	Grounded theory using semi-structured interviews	14 living donors	Explore what people experienced when deciding to donate a kidney and explore associated issues and concerned when they made their decisions	Korea
Sanner, 2003	Follow-up interviews 3, 6, 12 and 24 months post-transplantation	12 heart recipients, 12 living-kidney recipients and 11 necro-kidney recipients	To examine how organ recipients in late modernity conceived the special features that distinguish the transplantation from other treatments, namely that vital, “living” organ are transferred from one human being (deceased or alive) to another	Sweden
Franklin & Crombie, 2003	Retrospective semi-structured interviews between 1 and 5 years after transplantation (phenomenological approach)	50 donors and partners and recipients and partners (study A)	Not reported	United Kingdom
Haljamäe et al., 2003	Qualitative interviews (phenomenographic approach)	10 living donors	Assess and describe the remaining experiences of donors more than 3 yr after early recipient graft loss or death of the recipient	Sweden
Heck et al., 2004	Case studies by catamnestic interviews with donors and recipients	31 donor-recipient dyad	Examine the psychosocial effects of living donor kidney transplantation for donors and recipients under successful as well as complicated circumstances	Germany
Walsh, 2004	Semi-structured interview (interpretative phenomenological analysis)	8 living related donors	Explore psychological experience, motivation, and meaning associated with decision-making processes	Ireland
Andersen et al., 2005	Individual in depth interviews (empirical phenomenological method)	12 living donors	Explore physical and psychosocial issues related to the experiences of living kidney donors 1 wk after open donor nephrectomy	Norway
Sanner, 2005	Interviews the day before nephrectomy and 3 weeks afterwards	39 living donors	Explore the donation process of a heterogeneous group of genetically and non-genetically related living kidney donors	Sweden
Waterman et al., 2006	Focus group methodology	26 recipients, 4 donors and 3 family members	Understand the psychological barriers and educational needs of potential recipients regarding living donation	United States
Crombie & Franklin, 2006	Ethnographic interviews	50 donors, recipients and non-donors	Explore the family experience of live donation from psychological, social and cultural perspectives	United Kingdom
Andersen et al., 2007	Follow-up interviews (phenomenological approach)	12 living donors	Explore experiences regarding physical and psychosocial health during the first year after donor surgery	Norway

Brown et al., 2008b	Qualitative interviews (phenomenological approach)	12 living donors	Explore living kidney donors’ perceived experiences with the health care system from the period prior to being tested as a potential donor, through to post donation discharge and follow-up	Canada
Gill & Lowes, 2008	Interviews (phenomenological approach)	11 donor-recipient pairs	To explore the experience of donors and recipients throughout the live transplantation process and the relevance of the theory of ’gift exchange’ as a framework for exploring and understand donors and recipients experiences of live transplantation	England
Brown et al., 2008a	Semi-structured interviews (phenomenological approach)	12 living donors	Gain a deeper understanding of the decision-making processes and psychosocial issues for living kidney donors	Canada
Williams et al., 2009	Grounded theory using interviews	18 living donors	Explore and describe the experiences of persons who had donated a kidney within Western Australia	Australia

2.8 Table 2.2 Synthesis of findings

Table 2.2: Synthesis of findings with frequency effect size of each finding (how often a particular finding appeared in the body of literature reviewed) and intensity effect size of each study (how much each study contributes, in terms of the number of findings it includes, to the overall body of literature reviewed).

	Finding	Frequency Effect Size of Findings (%) ↓	Yi, 2003	Sanner, 2003	Franklin & Crombie, 2003	Haljamäe et al., 2003	Heck et al., 2004	Walsh, 2004	Andersen et al., 2005	Sanner, 2005	Waterman et al., 2006	Crombie & Franklin, 2006	Andersen et al., 2007	Brown et al., 2008b	Gill & Lowes, 2008	Brown et al., 2008a	Williams et al., 2009
	Intensity Effect Size of Studies (%) ⟶		14.8	11.1	20.4	14.8	22.2	16.7	24.1	31.5	13.0	18.5	16.7	22.2	33.3	29.6	7.4
DONORS	**Decision-making process**																
	Deliberation phase																
	Awareness of suffering	53.3				•	•			•	•	•		•	•	•	
	Altruistic and natural decision	46.7	•			•		•	•		•				•	•	
	Spiritual - philosophical decision	20.0	•					•								•	
	Carefully thought through decision	40.0	•					•	•	•				•		•	
	Quick and straightforward decision	13.3								•					•		
	Informative decision	26.7				•				•				•	•		
	Familial issues	53.3	•		•	•		•	•			•			•	•	
	No pressure	26.7				•			•	•					•		
	Intimacy with recipient	6.7	•														
	Threat - anxiety	26.7						•		•				•		•	
	Time of decision	13.3			•					•							
	Examinations : difficult stage	6.7								•							
	Withdraw possibility	13.3								•				•			
	Social support	20.0						•		•						•	
	Execution phase																
	Voluntary type	6.7	•														
	Compromising type	6.7	•														
	Passive type	6.7	•														
	At time of donation																
	Surgical experience																
	Just before surgery	20.0						•		•				•			
	Pain, nausea, exhaustion, scar	46.7							•	•		•	•	•	•		•
	Psychological strain	40.0					•			•		•	•			•	•
	Care experience																
	Positive experience	26.7				•		•		•				•			
	Negative experience	20.0								•		•		•			
	Wish for better psychological care	6.7								•							
	After donation																
	Medical follow-up	13.3											•	•			
	Concerns regarding future health	13.3					•		•								
	Living donation active promotion	6.7														•	
	Advices for others	13.3								•						•	
	Same decision again - no regrets	40.0			•		•				•	•			•	•	
	Back to normal	20.0											•		•		•
	Overall experience of donating a kidney																
	Complexity	13.3						•	•								
	Benefits for donors	53.3				•	•		•		•		•		•	•	•

	Donation : meaningful action	20.0							●				●			●	
	Being donor : unfamiliar trajectory	6.7							●								
	Conflicting donor roles	26.7							●			●	●	●			
	When transplantation fails	26.7				●	●						●	●			
RECIPIENTS	**Before donation**																
	Different ways of asking for a kidney	6.7									●						
	Wait for donors to volunteer	13.3									●				●		
	Accepting a kidney from a live donor	40.0		●	●		●				●	●			●		
	After donation																
	Being grateful to the donor	13.3			●										●		
	No regrets	6.7			●												
	Regrets	6.7			●												
	Benefits for recipients' health	6.7													●		
	Psychological strain	6.7					●										
	Negative experience	6.7					●										
RELATIONAL ISSUES	**Donor-recipient relationship**																
	Close, stable and possible improvement	40.0		●			●		●				●		●	●	
	Conflicts and deterioration	13.3			●		●										
	Familial aspects	13.3		●	●												
	Need to move on with their lives	6.7													●		
	Gift reciprocity and obligation to repay																
	No expectations from donors	20.0			●				●						●		
	Recipients' obligation to be grateful	13.3			●							●					
	Recipients' obligation regarding the graft	13.3										●				●	
	Recipients' gift to the donor	13.3		●												●	
	Recipients' gratitude	20.0		●			●								●		
	Way to reduce recipients' debt	6.7		●													

●: presence of a given finding.

2.9 Figure 2.1 Summary of the major themes of our metasummary

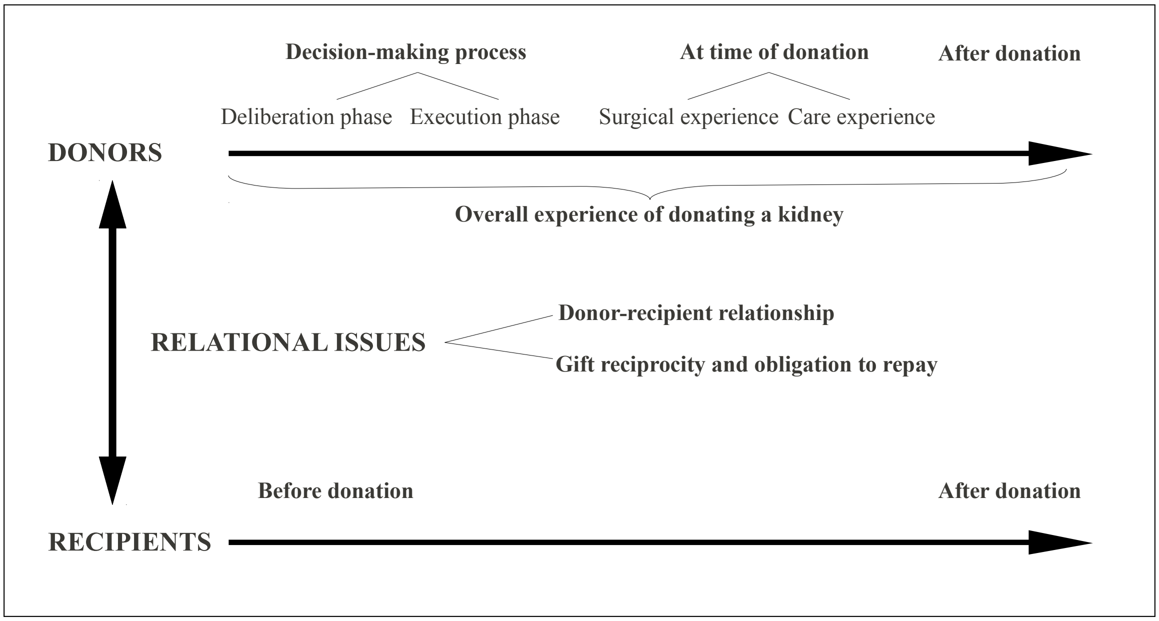

Figure 2.1: Summary of the major themes of our metasummary.

CHAPITRE 3

SECOND ARTICLE

Transplant Trajectory and Relational Experience Within Living Kidney Dyads

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3.1 Abstract

Living kidney donation is considered common practice across most Westernized countries. While extensive research has documented the experience of living donors, few studies have addressed the perspective of recipients, and even fewer have examined the experience of donor and recipient as an interactive dyad. In this study, our aim was to examine the reciprocal influence between donors and recipients across the transplantation process. We recruited a homogeneous sample of 10 donors and recipients, who were interviewed individually. Data were analyzed using interpretative phenomenological analysis. The presentation of results follows the stages of the transplantation process: the disease experience, the experience of offering and accepting a kidney, the screening period, the surgery, and the post-transplantation period. Results are discussed within the framework of Mauss's gift exchange theory, social roles, and altruism. This comprehensive description of the dyadic experience provides a way to frame and understand psychosocial aspects and relational implications of living renal transplantation.

Keywords: illness and disease, experiences; interpretative phenomenological analysis (IPA); interviews, semistructured; lived experience; nephrology; organ donation; psychology; psychosocial issues; qualitative analysis; relationships; research, qualitative analysis; surgery; transplantation.

Renal transplantation is now considered the treatment of choice in the event of end-stage renal disease (Knoll, 2008), as it allows for better medical outcomes (Jungers, Man, & Legendre, 2004) and higher quality of life for recipients (Glannon, 2008), is more viable economically than dialysis (Azar et al., 2007), and is considered safe for the donor (Segev et al., 2010). Living kidney transplantation (LKT) involves further advantages, namely better planning around the surgery, betteroverall graft quality, and longer graft survival (Crombie, 2006). In light of the continuing shortage of available grafts from deceased donors and the numerous advantages of LKT, it is actively practiced across several transplant centers. In Canada, LKT has represented 35 % to 37 % of all renal transplantations performed over the last decade, while the number of kidney transplants performed annually has remained stable (Canadian Institute for Health Information [CIHI], 2014). Similar trends can be observed in the United States where, nationally, living donation rates have remained essentially unchanged between 1998 and 2011 (Organ Procurement and Transplantation Netword [OPTN], 2012).

Living kidney donors have been the subject of much research. Several studies have described their decision-making process, their motivation to donate, their quality of life following donation and their reaction to the experience of donating a kidney (Ummel, Achille, & Mekkelholt, 2011). Results show that donors experience a sense of personal benefit and would reiterate their gesture, and that their psychosocial health remains unchanged or improves after donating (Clemens et al., 2006). In contrast, very few studies have examined the unique experience of individuals who have received a kidney from a live donor or the interaction between donor and recipient (Ummel et al., 2011), despite recommendations to focus on dyads as an avenue toward achieving an in-depth understanding of the donation process in its complexity (Sajjad, Baines, Salifu, & Jindal, 2007).

Organ transplantation reprensents much more than a surgical procedure, and unique issues arise at each stage of the transplant process, for both the donor and the recipient (Rybarczyk, Shamaskin, Gibson, & Huey, 2012). The literature suggests that rare but significant challenges to psychosocial and interpersonal adjustment may arise within donor-recipient relationship, the more severe being cases of depression, adjustment, or anxiety disorders developing despite the transplantation being a success and in the absence of medical complications for the donor (Fukunishi et al., 1998; G. C. Smith, Trauer, Kerr, & Chadban, 2003). Recipients are sometimes described as feeling indebted toward their donor, as if they owed something, a feeling that can at times be reinforced by comments and reactions within the family, particularly in cases of fraternal donation (Franklin & Crombie, 2003). Problematic relational issues are also likely to arise when a parent donates to his or her adolescent child, to the point where some adolescent recipients indicate they would have preferred receiving a graft from a deceased donor to avoid a possible sense of obligations toward, and possible future control by, their donor parent (Franklin & Crombie, 2003). Whether living-related donation by a parent to a child or adolescent may be associated with an increased risk of adverse psychosocial consequences for the recipient, manifested as poor self-management, suboptimalmental health, or an overwhelming sense of guilt and obligation toward the donor parent has been questioned (Aujoulat, Schwering, & Reding, 2012).

Ethical concerns associated with living donation have been raised both in the scientific literature and in the media. Question such as whether certain types of relationships (e.g., genetic relationships) create moral obligations and whether anonymous organ donation is an altruistic act have been debated by Glannon and Friedman Ross (2002). For these authors, "An altruistic act is one motivated primarily or solely by respect and concern for the interests and needs of others with whom one has no special relationship, freely chosen rather than done out of duty or obligation, and at some cost or risk to oneself." (p. 154). These authors state that distinct expectations and obligations arise when two or more people are involved in an intimate relationship, which are not in cases of anonymous altruistic donation. They propose that it is the intimacy of the relationship, rather than the biological bond, that creates a sense of obligation. Another framework that may help explain this sense of obligation is Mauss's (1990) anthropological gift exchange theory, which proposes that to make the gift circle complete, three interrelated obligations must be fulfilled: the obligation to give, the obligation to receive and the obligation to give back. These reflections on altruism, intimacy, and the cycle of giving guided our analysis of the data and discussion of the results.

In the present study, our primary purpose was to provide a better understanding of how LKT donors and recipients experience the transplantation process as an interactive dyad. Second, we wanted to examine the extent to which Mauss's anthropological gift exchange could be helpful in framing the dyadic experience of LKT. We anchored our research within a constructivist–interpretativist paradigm and adopted a phenomenological stance that involves interviewing those most concerned by the phenomenon under study. For the analyses, we chose interpretative phenomenological analysis (IPA; J. A. Smith, Flowers, & Larkin, 2009) as it allows for an examination of how people make sense of major life experiences, enables that experience to be expressed in participants' own words rather than according to pre- defined categories, and intends to provide a detailed understanding of human lived experience. IPA is particularly well suited for research in health psychology and several studies involving patient populations and IPA as a method of analysis have been published (e.g., Lafarge, Mitchell, & Fox, 2013; Ouellette, Achille, & Paquet, 2009; Pearce, Thøgersen-Ntoumani, Duda, & McKenna, 2014; Weston, Norris, & Clark, 2011.

3.2 Method

3.2.1 Participants

Our selection of participants targeted individuals who each had firsthand experience with LKT as members of a donor–recipient dyad. As such, we aimed for a homogeneous sample. Eligible participants had to have either donated or received a kidney between 6 months and 3 years prior to taking part in the study, be 18 years of age or older, and show sufficient proficiency in French to participate in a research interview. Ethical approval was obtained from the institutional review board prior to recruitment being initiated and the study getting underway. Participants were recruited in collaboration with the transplantation team of a university-affiliated hospital located in a large urban area and serving a primarily francophone population. We sent eligible participants a letter of invitation signed by the head nephrologist asking them to return a coupon to communicate their interest in participating. We ensured internal diversification (Pires, 1997) by means of purposive sampling: recruiting patients who presented different sociodemographic and medical characteristics other than the type of transplantation (e.g., gender, age, type of donor–recipient relationship).

The final sample comprised 10 participants representing five donor–recipient dyads. In IPA, sample size depends partly on the degree of commitment to the case study level of analysis and reporting, the richness of the individual cases, and the organizational constraints one is under. Because the primary aim is to provide a detailed account of individual experience, the issue is one of quality rather than quantity, and given the complexity of most human phenomena, IPA studies usually benefit from a concentrated focus on a small number of cases. J. A. Smith et al. (2009) recommend conducting between 4 and 10 interviews for an IPA study, a recommendation followed in prior studies (e.g., Oyebode, Bradley, & Allen, 2013; Rodriguez & Smith, 2014; Weston et al., 2011).

Five men and five women participated in the study. The mean age was 45 years (*M*=28–56 years, *SD*=8). The majority of participants were involved in a relationship (*n*=9). Six participants worked full-time, one worked part-time, one was on leave from work, and two were retired. Three recipients had been on dialysis before transplantation and two had not. Three donor–recipient dyads shared a genetic relationship (in two cases, a sister gave to her brother; one mother donated to her daughter), one dyad was emotionally related (a wife donated to her husband), and one was casually related (a colleague donated to a fellow worker). Time elapsed since surgery when the interview took place varied from 8 to 32 months post-transplant (*M*=21, *SD*=9).

3.2.2 The interviews

The first author conducted in-depth individual interviews lasting between 37 and 90 minutes with each participant separately. Interviews took place either at the transplantation clinic (*n*=5), the participant's place of residence (*n*=4), or at their workplace (*n*=1) according to each participant's preference. Interviews were digitally recorded, transcribed verbatim, and checked for accuracy (Kvale, 2007). The interview was open in nature, and began with a general inquiry: "Tell me how you came about (giving a kidney for/receiving a kidney from) live kidney donation?" The interviewer used reflection and reformulation strategies to further the exploration of participant's experience, and adhered to the interview schedule in a flexible manner to allow the focus to remain on issues that were important for each participant. Participants were also encouraged to talk openly about issues relevant to them. To protect confidentiality, no information was shared with participants that had been provided by the other member of the dyad. At the end of the interview, we inquired about each participant's experience of the interview process and asked them to fill out a short sociodemographic questionnaire.

3.2.3 Data Analysis

We conducted data analysis using IPA (J. A. Smith et al., 2009), an idiographic approach concerned with the close examination of each individual case to understand how participants make sense of their experience while recognizing that this process requires interpretation by both the participants and the researcher (Dancyger et al., 2011). More precisely, IPA data analysis comprises six steps. In the first step, we read and reread the first transcript several times to become immersed in the original data. In the second step, initial noting, we examined semantic content and language and added descriptive, linguistic, and conceptual comments to the transcript. In the third step, we developed emergent themes, and in the fourth step, we searched for connections across themes. In the fifth step, we moved to the next case and repeated the first four steps for each of the other 9 participants. In the sixth and last step, we looked for patterns across all 10 participants.

3.2.4 Quality and Trustworthiness

In constructivist or phenomenological inquiries, authenticity is considered an important criterion and involves providing a fair description, meaning that "all stakeholder views, perspectives, values, claims, concerns, and voices should be apparent" (Lincoln, Lynham, & Guba, 2011, p. 122). Throughout the research process, we made deliberate efforts to ensure that all participants had their stories treated fairly and with balance, from the interview to the final redaction. This was particularly true during data analysis, where the interpretative process included different theoretical perspectives and where reflexivity was considered crucial. To maintain reflexivity, "reflecting critically on the self as a researcher" (Lincoln et al., 2011, p. 124), the first author engaged herself in a conscious effort to acknowledge her assumptions of the phenomenon under study and take into account the potential impact of her subjectivity on the data. This was achieved by keeping rigorous reflexive notes in a journal during initial readings, interviews, and data analysis as recommended by Morrow (2005), and by engaging in reflection and discussions with the second author throughout the research process.

3.3 Results

To respect the spontaneous chronology of participants' accounts and to illustrate their dynamic and dyadic perspective, results will be presented according to the following five phases of the transplant process: (a) the experience of the disease, (b) the experience of offering and accepting a kidney, (c) the screening period, (d) the surgery, and (e) the post-transplantation period ending with the time the interview took place.

3.3.1 The Experience of the Disease

Even several months post-transplant, the experience of the disease, and in some cases the experience of dialysis, was still present in the recipients' discourse. For some recipients, renal disease was a short-lived episode, whereas for others, renal disease had been a long-term, chronic condition. Recipients for whom renal disease had constituted a recent and sudden diagnosis all stated that they had first reacted by being in denial of their illness and of the need for dialysis and transplantation. While this type of reaction was less often described by those who had a more chronic experience with the disease, at least one recipient who had been diagnosed more than 10 years prior to receiving a transplant described a comparable reaction of denial. Denial was expressed in reaction to several aspects of the disease experience and treatment, including the need for dialysis, and for those who did not have to undergo dialysis, in reaction to the confines of immunosuppressive medication. Recipients who did not mention anything negative regarding medication were those who clearly stated that they perceived transplantation as an ongoing form of treatment rather than as a cure. Some recipients expressed feelings of guilt regarding having kidney disease.

> *"Well, you feel guilty, I dunno, you feel … it took me, it took me a while to accept it. … Especially when you go through, you go through all the disease, you have more attention than the other [sister], so this, I felt, I didn't feel well, I felt guilty from all this, that this was happening to me."* (Recipient, genetic relationship)

> *"I think that it [the transplantation] changed everything in my life. You no longer feel the guilt you felt before."* (Recipient, casual relationship)

Recipients who were transplanted without having experienced dialysis first considered their disease experience as having been less difficult than those who had to undergo dialysis first.

> *"I'm very lucky because I haven't done any dialysis."* (Recipient, emotional relationship)

At this stage of the process, donors did not yet play an active role. Some were aware of the future recipient's disease and of its deteriorating course, but in other cases, the disease onset was a surprise for both the donor and the recipient.

3.3.2 The Experience of Offering and Accepting a Kidney

Both donors and recipients reported that it was the donor who had offered to give a kidney, in some cases at the time the diagnosis of renal disease was announced and in other cases when dialysis became a serious consideration. Recipients described their initial reaction as refusal, surprise, an inability to understand this gesture, feeling like they had no choice, ambivalence, and guilt about needing a graft. Most recipients emphasized that their donor had reiterated his or her offer several times.

> *"First, when she announced it to me ... she simply announced it ... in front of all the members of my family, and, I was surprised, I mean, at that moment, I was surprised. You know, it's not that I didn't believe it, it's more the question you know, that maybe I wasn't realizing 100 % what was happening to me."* (Recipient, genetic relationship)

> *"[The donor] calls me to tell me he wants to give me one kidney, I said no, I didn't understand why. Because he wasn't someone I would go out with outside of the job or something like that, he was really only a colleague."* (Recipient, casual relationship)

> *"I think that I have had 5 or 6 surgeries so I couldn't imagine that someone would deliberately choose to have one, without it being necessitated by any health issue I mean. That he wanted to suffer to help someone, hum, I didn't really get that. I am not even sure that me, as a person on dialysis, I would have done the same you know."* (Recipient, casual relationship)

> *"She [donor] told me about it [donation] one year before and, at that time, it was a categorical refusal. ... It was out of the question, I was maybe still a little bit in a denial phase, well, that I wouldn't have to go through this, that this wouldn't happen."* (Recipient, genetic relationship)

> *"Well, it's just that the first time she spoke to me about it [donation], I wasn't really, I wasn't ready for that. But in the following year, it was so difficult that you are constantly thinking about that."* (Recipient, genetic relationship)

Eventually, all recruited recipients accepted the kidney that was offered, and we found that time and reflection had been necessary for many recipients to finally accept. Some described their willingness to accept as justified by a sense of reciprocity, which characterized sibling relationships. Other recipients recognized the absence of an alternative in their decision to accept, or described that receiving a kidney did not result as much from their choice to accept but rather from the donor's prerogative to give.

> *"And, I didn't have any choice, it was her [donor's] choice."* (Recipient, emotional relationship)

In the context of a donation between colleagues, the recipient emphasized the role of the multidisciplinary team in influencing his decision.

> *"It's even the social worker or the psychologist at the hospital who convinced me to accept it [the kidney]."* (Recipient, casual relationship)

3.3.3 The Screening Period

Once the offer was accepted by the recipient, donor and recipient had to go through the pre-transplant screening. Donors described this phase as long and involving many steps that necessitated being available for multiple tests and medical appointments. On an emotional level, this period was described as particularly stressful and some donors reported having had no one with whom to share their fears and worries regarding the testing and donation process, which was often experienced as isolating. This is consistent with an earlier description of donation as "a journey through perseverance and patience" (Clarke, Mitchell, & Abraham, 2014, p. 399).

Recipients did not focus as much as the donors on the screening period, but one recipient emphasized the rigor involved, and some recipients described this period as stressful and difficult, to the point where one recipient would have liked to stop the donation process. One recipient said that he guarded himself from becoming too hopeful by reminding himself of all the steps they had to go through before receiving confirmation that the surgery was indeed going to be possible. Additional results specific to the screening period have been published in more detail elsewhere (see Ummel & Achille, 2014).

3.3.4 The Surgery

The majority of donors described the surgery as a pleasant experience or adventure. Regarding the risks involved, some mentioned having experienced pain and aches after the surgery, more intense than what had been experienced in the context of previous surgeries in the case of one donor. Only one donor reported a serious complication, as part of his intestine had been clipped during surgery, which made his recovery more troublesome and painful. This event also had an impact on his recipient, who worried.

The surgery appeared to be an event of less importance and meaning for recipients, who focused more on the extremely positive experience of having received a new organ than on the surgery itself. Those who spoke about the surgery stated that the process had gone well. Some indicated that their hospitalization post-surgery had seemed long and had been particularly wearisome toward the end.

3.3.5 The Post-Transplant Period

All recipients in our sample described the transplantation as a positive and life-changing experience, a gift that allowed them freedom and gave them a new lease on life.

> *"It's, hum, the most beautiful event that happened in my life, let's say that it was an incredible gift."* (Recipient, casual relationship)

For donors, the act of giving was clear-cut: after donation, the kidney no longer belonged to them, and the recipients did not owe them anything.

> *"It belongs to her, I remember this, I wrote her a letter, I told her, it belongs to you, no longer to me, you can do whatever you want with it."* (Donor, genetic relationship)

Some participants stated that their relationship with the other member of the dyad had evolved or changed but without being able to really explain how this change had occurred or what had changed. What we noticed is that their descriptions suggested that some relationships reached a sort of closeness, as if the relationship had evolved to a new dimension as a result of the donation experience. Most interesting was that the specific interpersonal and social context within which the donation took place was important in shaping the discourse that emerged from each dyad. In the context of genetic relationships, giving seemed an extension of the role donors adhered to in a larger social context and receiving was easily integrated. In the case of a parent-to-child donation, for example, giving a kidney was clearly described as a natural gesture by the parent:

> *"You know . . . they are our children, and our children shouldn't die, or shouldn't be sick before us, parents."* (Donor, genetic relationship)

In sibling relationships, we found themes of reciprocity, equality, rivalry, and justice.

> *"He was my brother you know. I love him deeply, and well, I found him too young to die, passing away like that didn't make any sense to me. It didn't make any sense, and I had to find a way to make some sense out of this."* (Donor, genetic relationship)

> *"And for me, if she had been the one with the disease, it's clear that it would have been automatic for me, or even [for] my other younger sister [to do the same]."* (Recipient, genetic relationship)

> *"Hum, the way I see it is that if the situation had been reversed, I would have given without hesitation."* (Recipient, genetic relationship)

These themes were also found in the context of other donation relationships, as one adult child recipient expressed that in her process of accepting, she had considered her sibling and her sibling's potential need for a graft.

> *"It took me a lot of time to accept it, because, I don't know, I thought of my sister, I was asking myself: why would I have one of our mother's kidney, and what if one day, I knock on wood, but what if one day something happened, [our mother] wouldn't be able to help her, I don't know."* (Recipient, genetic relationship)

Within casual relationship, meaning making was less easily achieved and there was no social norm to refer to in the process of making sense of the donation.

> *"This was difficult to accept, because it's a person you know, in a certain way, but it's not family. If it had been family, I think it would have been a little bit easier hum [silence], I think so, I don't know. But, hum, no, it was difficult knowing that a stranger gave me a kidney."* (Recipient, casual relationship)

In terms of being a live donor, we found that the meaning of giving a kidney was multifaceted and differed between donors. Not only did the description of this meaning evolve and take shape along the course of the interview but making sense of it was facilitated when the larger social and relational context of the relationship was considered. In the cases of the sisters in our sample who gave to a brother, giving seemed a personal, natural, and automatic decision, a necessity that was congruent with personal values, despite the cost of having to undergo a surgery.

> *"This is really a personal choice, it belongs to you. Nobody can influence you on such a choice, it's your body, it's your life, it's your risk."* (Donor, genetic relationship)

> *"And I had known it for eleven years already [that I was to give my brother a kidney]."* (Donor, genetic relationship)

Some donors also referred to a sense of self-interest, the importance of being able to give, and being able to give was what mattered most to them.

> *"If I hadn't given to him, I would have given anonymously."* (Donor, casual relationship)

> *"I did it because I wanted to, and I even told him that it was egoist, that I did it out of egoism, pure egocentricity."* (Donor, genetic relationship)

> *"Yes, knowing that everything was ok, that all the tests were good, it's, hum . . . [in a softer voice], that's what was important."* (Donor, genetic relationship)

Last, there was also a private, symbolic meaning associated with the gesture of donating, a meaning that represented the stance the donor adopted with respect to the recipient. For one sister, seeing her brother on dialysis was like seeing him drowning, she had to dive in and save him. Giving was a sort of duty, which, once accomplished, was followed by the relief of knowing that one's duty was done and of not having to feel guilty anymore.

> *"If I sat on the riverside and I saw him drowning, I told him, I wouldn't be able to just watch. I would say: I am going to get him, and if I fail, at least I will have acted according to my own values . . . but if I sit and I say: no, the water is too cold . . . and I look at him drowning, I wouldn't be able to live with myself."* (Donor, genetic relationship)

For a spouse, giving a kidney to her husband symbolized her willingness to renew her commitment to him and to their relationship, even though they had already been married for 20 years and had two adult children.

> *"For me, I knew that if I gave the kidney, in my mind, it was that I was committed to staying with this person for a long long time, you know, that I had enough love to continue to go through life with him."* (Donor, emotional relationship)

For one sister who had chosen not to have children, giving her kidney was a way of giving life that she compared to motherhood.

> *"Well I say to myself, I didn't give life by giving birth to a child, but finally I offered my brother a second life! ...Because they cut me to take the kidney out, that was like a c-section if you want."* (Donor, genetic relationship)

3.4 Discussion

In the present study, we aimed at providing a better understanding of how LKT donors and recipients experience the transplantation process as an interactive dyad. We also aimed at examining the extent to which Mauss's anthropological gift exchange theory provides a framework that facilitates the conceptualization of their experience.

First, in light of how participants described their experience, it is undeniable that for both donors and recipients in our study, transplantation was a positive experience. For recipients, the transplantation was typically described as a life-changing event, and for donors, the donation process and the gesture of giving itself was associated with a sense of self-fulfillment as well as with the satisfaction of witnessing improvement in the recipient's health and quality of life. This is consistent with prior research (Clemens et al., 2006; Ummel et al., 2011) and supports once more that LKT carries benefits not only from a biomedical perspective but also from a psychosocial one. This finding is particularly meaningful at a time when LKT is actively being promoted in many centers and further expanded through novel avenues such as paired exchange and altruistic living donation.

We also found that for each donor–recipient dyad, the transplantation process reflects the unique larger social and interpersonal context within which the dyad evolves, and we propose that the decision to give or accept a kidney becomes a reflection of the social role one adheres to with respect to another being in everyday life. In genetic relationships, the gesture of donating proceeded according to one's role in the family above and beyond one's role as an individual (Rougeul, 2012), thus constituting an "extension of ordinary kinship obligations" (Crombie & Franklin, 2006, p. 208). From a social psychology perspective, a role is "the behavioral expectations for what a person 'should' do when occupying a position (status) in a specific social setting" (Zurcher, 1983, p. 223), and a social role is "a behavioral repertoire, characteristic of a person or a position; a set of standards, descriptions, norms, or concepts held for the behaviors of a person or a social position" (Biddle, 1979, p. 9). In other words, social roles are defined by duties, norms, and expectations, and when social role enactments are consistent with the self, one is more likely to perform well and in turn derive feelings of effectiveness within that role (Bettencourt & Sheldon, 2001). Enactment of social roles allows for the satisfaction of three basic psychological needs: autonomy (the desire to self-organize experience and behavior, and to "have activity" with one's integrated sense of self), relatedness (the desire to feel connected to others, to have a sense of communion or closeness with others), and competence (the feeling of efficacy, of being able to achieve what one sets out to do) (Bettencourt, Molix, Talley, & Sheldon, 2006; Talley, Kocum, Schlegel, Molix, & Bettencourt, 2012). Thus, in genetic relationships, when a mother or a sister chooses to give a kidney to a daughter or brother, she succeeds in fulfilling autonomy (she makes her own decision), relatedness (she takes care of a close one), and competence (she performs a valuable gesture and potentially gains benefits from it), and the fulfillment of the needs results in enhanced psychological health (Talley et al., 2012). In contrast, in the context of casual and emotional relationships, this process appears more complicated. In the case involving colleagues (casual relationship), the donor demonstrated a high level of autonomy in his decision to donate and felt competent giving the kidney, but the relationship with the recipient was neither close nor intimate and therefore did not meet the criterion for relatedness, which may explain why it was more difficult for the recipient to make sense of the donation. Within the dyad involving a spousal donation (emotionally related dyad), the fact that the recipient was ambivalent about receiving and accepting a kidney from his wife may have represented an attempt on his part to affirm his autonomy, but doing so challenged his wife's feeling of relatedness to him and her sense of competence in helping him, their couple, and their family. This may explain the relational issues and difficulties both members of the dyad experienced before donation. It also echoes findings from a German study that examined the relationship between donor and recipient in the context of living donor liver transplantation and concluded that the kind of familial relationship or non-relationship bears an important influence on perceived mental burden and emotional quality of life for both members of the dyad (Erim et al., 2012). For example, adult children who donated to their parent demonstrated greater anxiety and depression, as well as elevated mental burden and reduced emotional quality of life in comparison with healthy non-donor controls and other types of donors (parents donating to their children, siblings, spouses, and other related and non-related donors). This finding is explained by the authors as reflecting a lack of choice for the donor based on social expectations. On the contrary, parents who donated to their adult children obtained lower scores on anxiety and depression in comparison with healthy non-donor controls, which the authors interpreted as a demonstration of parents' motivation to have an influence on their child's suffering, which is in turn typically associated with an absence of ambivalence in the decision-making process. This is coherent with what we observed in our own findings.

Donors have different reasons and motivations for donating a kidney, and the sense they make of giving is complex and multifaceted. We found that even if this decision occurred within, and seemed influenced by, a larger social and interpersonal context, donors described it as highly individual and personal, as if they were cognizant of the broader context they were a part of but still needed to believe they had personally chosen to pose the gesture to make it their own decision. Donors also described their decision as self-interested, which echoes the moral obligations of genetic relationships (Glannon & Friedman Ross, 2002). With regards to altruism, often referred to as one of the fundamental principles of dona tion, in particular deceased donation and living altruistic donation, whether it is applicable to the context of living donation remains at the heart of a debate, especially since the definition of the concept itself varies across different philosophical perspectives (Moorlock, Ives, & Draper, 2014). Together with Glannon and Friedman Ross (2002), we argue that living donors involved in emotional or genetic relationships are not driven by altruism, but rather by a sense of duty that they must and absolutely want to fulfill to enhance the recipient's health, and also because it allows them to play an active role in the process, a role that is coherent with their social obligations. The fact that several donors associated a personal meaning to their donation, a meaning that went beyond improving a loved one's health, is also in contradiction with the idea of altruism. Giving a kidney to a spouse as a symbolic renewal of vows or to a sibling as a symbolic gesture of giving life, as one might have by having children were powerful illustrations of how donors could find meaning in what is otherwise a primarily surgical and biomedical procedure. In contrast, in the context of a casual relationship between two people who are not involved in an intimate relationship and where no clear obligation or duty to help a close one exists, the motivation can be seen as altruism and closer to anonymous altruistic donation. Some aspects of the donor's experience within this type of dyad echo the experience of altruistic LKT donors described by Clarke et al. (2014), namely, seeing oneself as a donor on the basis of other actions already accomplished (e.g., giving blood).

The donation process can be further discussed within the framework of Mauss's (1990) gift exchange theory, which describes three obligations that are interrelated: to give, to receive, and to give back. In our study, donors could feel pride or relief, and therefore derive benefits from fulfilling their obligation to give, but fulfilling the obligation to receive was more difficult for recipients. All recipients initially refused to receive the kidney they were offered, and it is only later, after having hesitated and reflected, that they did finally accept it. In this sense and in accordance with gift exchange theory, recipients, whose only alternative is dialysis may not feel like they have a real choice and ultimately may feel obligated to accept. From a clinical perspective, recipients' initial refusal is important to take into consideration. Transplantation teams should be aware that this initial refusal is typical and support the recipient in his or her decision-making process. Those caring for candidates to donate should inform them that it is common for an intended recipient to react this way and to need time before accepting. From a critical perspective, one could argue that this initial refusal may reflect an attempt to act in a socially desirable way in reaction to feelings of guilt for being in need of a kidney and wanting one. By initially refusing the kidney and letting the donor reiterate his or her offer, the recipient may be testing the donor's readiness and level of commitment, making the decision to accept easier. Regarding Mauss's third obligation, to give back, in the context of genetic and emotional relationships, donors defended against having wished for something in return for their gesture, even if some stated they had received a medal for bravery or a form of gift from their recipient, and recipients did not express feelings of indebtedness toward their donor. In contrast, in the context of a casual relationship, the obligation to give back was more present for the recipient, especially because the donor was unwilling to accept any kind of gratitude, which made it particularly difficult for the recipient to integrate and make sense of his donor's gesture. Diverging perspectives between recipient and donor regarding the importance of giving back seemed to have left the cycle incomplete, resulting in difficulties making sense of the experience for the recipient, who could not imagine reciprocity in this context.

The study has limitations, namely, that data were collected post-transplantation only and therefore subject to a retrospective bias. Also, participants were recruited from a single transplantation center and we were unable to recruit a dyad involving an adult child giving to a parent. Finally, by choosing a constructivist position, our values and interests were part of the cycle of interpretation, and we acknowledge that our interpretation is shaped by our training in psychology.

Despite these limitations, the study's unique contribution includes providing a rare insight into the experience of donor–recipient dyads in their own words, and bringing to our awareness how the type of relationship donor and recipient are involved in and the social role and relational obligations unique to this relationship appear to have a profound impact in shaping the donors' and recipients' experience. The experience of giving, or receiving, is facilitated when it is coherent with the enactment of a social role that allows basic psychological needs to be fulfilled: autonomy, relatedness, and competence. Receiving may be especially difficult in instances when fulfillment of one of those needs cannot be easily achieved (e.g., relatedness). Giving back seems neither desired nor necessary when basic psychological needs are fulfilled.

In terms of future research, a longitudinal design involving several interviews completed both prior to and after transplantation, as well as a combination of separate and joint interviews, would allow for an even deeper and more complete understanding of the overall relational issues associated with living donation. In addition, studies conducted with specific types of dyads (e.g., child to parent) could help identify issues specific to each relational context that health care teams need to be aware of to prepare, monitor, and support each member of the dyad throughout the process of donation and transplantation.

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CHAPITRE 4

THIRD ARTICLE

How not to let Secrets out When Conducting Qualitative Research With Dyads

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4.1 Abstract

Confidentiality is one of the cornerstones of research involving human participants. Researchers are the first-line gatekeepers of their participants' right to confidentiality and situations arise that pose a challenge to this responsibility. This is the case when individuals who have shared a common experience (i.e., dyads) are interviewed separately but results emanating from their interviews are disseminated in a dyadic perspective. Based on our experience of conducting research with dyads and considering the limited literature available to guide us, we set out to write the present article to share the knowledge we acquired and the solutions we found. The present article describes both the ethical challenges and methodological decisions involved in conducting qualitative research with dyads. The article also describes different modalities of dyadic analysis, their benefits and drawbacks. This endeavor seems especially relevant as research involving dyads is emergent in several domains involving couples, families, caregivers and health.

Keywords: Confidentiality / privacy, data collection and management, disclosure, ethics / moral perspectives, interviews, qualitative analysis, relationships, research design, research, qualitative.

"A case is made for the importance of dialogue among qualitative researchers so that the researchers learn collectively from the difficulties and problems that they have encountered individually." (Boman & Jevne, 2000, p. 547)

Confidentiality is one of the cornerstones of research involving human subjects. It is guaranteed to participants to provide them with the safe context that will allow them to share their innermost secrets while safeguarding their right not to be identified and not to suffer from prejudice on the basis of the information they share. It is an essential feature of any research that seeks to get as close as possible to an authentic description of a person's experience of a given phenomenon. Protecting research participants' right to confidentiality is a responsibility that is shared by researchers, institutional review boards, and participants themselves. The role of the researcher as gatekeeper of participants' confidentiality is well described in research guidelines and disciplinary code of ethics (e.g., American Sociological Association Code of Ethics or Canadian Code of Ethics for Psychologists). Confidentiality can be broken down into traditional (or external) confidentiality and internal confidentiality. For Tolich (2004), "traditional" or external confidentiality involves a commitment by the researcher that while the content shared by a given participant may appear in a publication or other forum for results dissemination, the participant himself or herself will not be identifiable. Internal confidentiality is a less apparent aspect of confidentiality and refers to the possibility that research participants involved in a common study will be able to identify one another on the basis of information appearing in a publication or other form of presentation. Failing to insure internal confidentiality can potentially harm research participants who know one another and who may find out things about one another they were not supposed to know.

Internal confidentiality warrants particular attention in qualitative research for two reasons. First, because qualitative researchers, in keeping with the inductive nature of qualitative research, often conduct in-depth interviews or participant observations that involve smaller samples than is typical in quantitative research, and second, because the presentation of findings often includes participants' verbatim. Both make it more difficult to insure that the information cannot be traced back to an identifiable participant within a small group. This becomes an even higher concern when qualitative research is conducted with dyads involving individuals who have shared an intimate, common experience, especially when this research takes place in a health care setting where individuals may be facing a crisis or their time may be limited and precious. Protecting internal confidentiality is of the utmost importance when there is a risk for emotional harm in the event that participants find things out about one another that were not intended to be shared (Morse, 2007). In those contexts, committing to the protection of confidentiality of words and images shared by participants within the research process can be a challenge for the researcher.

In our recent research experience, we were caught between having a responsibility to protect internal confidentiality among our research participants, who were members of dyads interviewed separately, and wanting to illustrate our findings rigorously and with sufficient details to present a dyadic perspective (i.e., both sides of a common experience across time). Our aim was to describe, on a dyadic level, how donors and recipients of a living kidney donation experience the donation process and the relational issues involved. To do so, we selected different types of dyads (sister donor-brother recipient, mother donor-daughter recipient, wife donor-husband recipient and donation between colleagues), which made it even more difficult to illustrate results in a confidential, anonymous manner. It therefore became quite clear that presenting results from a dyadic perspective may pose a threat to internal confidentiality. As we turned to the literature for guidance on how to resolve our dilemma, we came across examples of results that were published without consideration for internal confidentiality, but little to inform us on how to proceed with our own presentation of data. From that point on, we decided to adapt our presentation of findings in a way that would optimize internal confidentiality even though it implied not presenting precise dyadic findings and keeping our result dissemination at a more general, and therefore less identifiable, level (for further details please see Ummel & Achille, 2015).

This experience led us to a broader reflection on the ethical and methodological challenges of doing research involving dyads. Given the timeliness of research involving individuals sharing a common experience (e.g., dyads husband and wive, same-sex partners, patient and caregiver, mentor and apprentice, or small groups like families, classrooms, or divisions in a workplace), we propose to share our reflections and recommendations to help inform others and encourage them to think preemptively about the issues specific to doing research that involves participants who have shared a common experience. Our reflections and recommendations will be presented in the typical chronology of the research process: (a) recruitment, (b) consent to participation, (c) data collection, (d) transcript validation by participants, (e) data analysis, and (f) result dissemination.

4.2 Recruitment

In this first stage of recruiting dyads, which may look relatively simple, there are issues to consider and careful decisions to make that will potentially impact all other stages of the research. First, there is a challenge related to the inclusion of both members of the dyad from the outset. If during recruitment the message that is sent to eligible participants is that dyads are being recruited, then even if the involvement in the research is meant to be voluntary, the weight of a possible "subtle" pressure to participate if one member agrees to participate but the other is unwilling or unsure should not be underestimated. Each member of the dyad should be given the opportunity, individually, to choose to become involved or not, and the option to withdraw without explanation. Otherwise, this could result in an intrusion of the relationship into the recruitment process (Forbat & Henderson, 2003). In contrast, by not stating clearly at the outset that both members of the dyad will participate in the study, the discussion about the extent to which confidentiality will be protected between members of a dyad could become more challenging, as we present later.

For our project, our aim was to recruit dyads involving donors and recipients of a living kidney donation. However, it soon became apparent that we wanted each member of the dyad to consent freely to participate, without being influenced or obligated by the consent of the other member. We therefore cast solo invitations to donors and recipients independently. The nurse coordinator of the clinic where recruitment took place sent an invitation letter to all donors and recipients who met our inclusion criteria (for more details please see Ummel & Achille, 2015), along with a coupon to be returned by those interested in participating. It is worth noting that to protect each individual's ability to make a voluntary decision, the letter did not specify that the other member of their dyad would be recruited for the same study nor that our goal was to identify dyads of consenting members. It is only after having received the coupons that we selected participants whose corresponding member was also willing to participate.

4.3 Consent to participation

Once both members of a dyad have agreed individually to participate in a research project, the consent process necessitates that participants be informed of the extent to which, and the mechanisms by which, confidentiality will be maintained. The possible limits to external and internal confidentiality, if any, should be clearly delineated during this process. Some researchers, as we did, commit themselves to protecting the confidentiality of both members of the dyad, at the risk of limiting the format in which findings can be disseminated. Another possible avenue, however, is to offer a limited confidentiality, in the sense of making explicit the risk that some verbatim or other information could be recognized by the other member of the dyad in a final publication. In other words, this would mean that the researcher clearly states that external confidentiality will be protected but that internal confidentiality could be compromised if one participant recognizes him or herself in the data and learns information about the other member of the dyad by association. In this scenario, participants should have an opportunity to give consent after having been informed clearly about this possible "loss" of internal confidentiality. However, a question remains as to the impact this limit to confidentiality may have on the quality and depth of the data collected by means of interviews. This is another important aspect to keep in mind and reflect upon prior to engaging in research involving dyads. Needless to say, each member of the dyad should be given an opportunity to complete the consent process independently from the other member.

4.4 Data collection

There are two main ways of collecting data from dyads: conducting separate or conducting joint interviews. Many variations can be found along the continuum spanning those two modalities. In our research experience, our priority was to get information that was as personal and detailed as possible from each member of the dyad, so we purposively decided that each member of the dyad would be interviewed separately by the same interviewer (the first author). At the time of the interview, we were primarily concerned with ensuring our participants that the other member of their dyad would not have access to any information provided by them. Pragmatically, we tried as best we could to interview both members of each dyad as close in time as possible, and we started with the first member who was available (thus leading us to interview the donor first once and the recipient first four times). Before conducting the second interview within the same dyad, the interviewer read and re-read carefully the entire transcript from the first member in order to be as aware as possible of the information that had been provided by each member of the dyad. Rigorous reflexive journal notes were taken during this process in an effort to be aware of threats to confidentiality and to think on an ongoing basis of how to best protect the confidentiality of each member.

The literature was helpful in alerting us to the many biases that risk intruding the research process in contexts where research participants know each other and share a relationship. First, the researcher conducting the interviews can perceive an imbalance within the relationship that he or she is researching. Preference could be given to the account or discourse of one member of the relationship over the other's (Forbat & Henderson, 2003). To counter this, one aspect of rigor in qualitative research is fairness (Morrow, 2005), which consists of representing participant viewpoints equitably and avoiding lopsided interpretations that are tainted by the researchers' own biases or by the perspective of only a few participants. When working with dyads, the researcher has the potential to position himself or herself in the relationship and, either intentionally or unintentionally, to prioritize one participant's perspective over the other's. Despite trying as hard as possible to consider both perspectives, the researcher will form different connections with different participants on a human/emotional level (Forbat & Henderson, 2003), and thus a reflexive process is important to acknowledge when this is happening. When imbalance occurs at a high level, rigor is compromised and fairness is no longer maintained.

In addition, instances may come up when the researcher is asked, explicitly or implicitly, to take sides within the relationship. There is then a need to insure that the information from one party is not communicated to the other party, as the researcher must not become the messenger between the two. This indicates a need for early thinking about how confidentiality will be maintained between research participants, as we suggested earlier in relation to the recruitment phase. In our own research, our line of conduct was clear: we did not even mentioned to each member of the relationship that we were meeting with the other person or whether the other person's interview had been planned or conducted. We also tried to interview both members of a dyad as close in time as possible, in order to lower the risk that they would speak to one another between the interviews. During the course of each interview, the interviewer aimed to stay as neutral as possible when a member of a dyad, who was interviewed second, explained facts associated with an event that had already been discussed during the interview conducted with the first member. However, as we will illustrate later, staying close to this line of conduct can be more challenging when a participant asks a precise question regarding the other member of the dyad.

Other options exist in terms of interviewing dyads jointly or separately that we will present in the following paragraphs, along with their pros and cons.

4.4.1 Separate interviews performed by the same interviewer

Conducting separate interviews performed by the same interviewer enables each protagonist to tell the story from her or his perspective, without having to take into consideration the reaction of the other person when criticism are voiced or sensitive topics are brought up (Eisikovits & Koren, 2010). Separate interviews enable an examination of overlaps and contrasts between the individual versions, which provides access to the individual's subjective version. This provides an opportunity to capture the individual's subjective version within the dyad without relinquishing either the dyadic or the individual one (Eisikovits & Koren, 2010). However, when separate interviews are performed, this sets limits on the possible interpretations of each individual's material, as the other partner's version cannot be entirely ignored or disregarded.

Nonetheless, the absent partner remains virtually present in the interview space. The possible influence of the interview that was completed first on the second interview is perhaps the most challenging aspect of doing separate interviews. One participant might bring up a topic of interest to which the other participant makes no reference. Although this topic may be of great relevance to the research question, it is a challenge to decide how far the researcher can go in introducing this topic to the second participant. It is worth reflecting upon the extent to which second interviews are influenced or guided by the first ones. As we will address it in the next section, Forbat and Henderson (2003) recommend having different interviewers conducting individual interviews separately with each member of the dyad simultaneously to prevent this carry over effect, but this also implies a loss of rapport between the researcher and the participants. To some extent, the issue of influence is addressed by reflecting on the contextualized nature of the interview as a social interaction. All interviews will be affected to a greater or lesser extent depending on our interpretation of a number of features. Such influence occurred at several moments in our own research. For example, in a first interview within a dyad, one donor explained in great details the gift she reported having received from her recipient. Later, when the recipient was interviewed, he briefly mentioned the same event, but without ever stating that he was the one who had actually given the gift. Even though the notions of gift-giving and giving back were central to our research question, the interviewer did not ask specific questions about this event and instead tried to take into consideration the information from the context of each single interview, even thought this was challenging. Inevitably, it felt as though some potentially interesting data were lost, but it allowed us to maintain an ethically defensible position.

Separate interviews can also give rise to a number of ethical issues, namely the difficulty to maintain confidentiality between members of the dyad when information is validated or when divergent versions are contrasted. The dyadic analysis might also compromise internal confidentiality, as each member can recognize the other member in the dyadic presentation, as we described above. Eisikovits and Koren (2010) suggest choosing separate interviews when researching sensitive topics, but not exclusively in those instances, as many types of dyads, namely couples, have topics that remain private and are not shared. However, Taylor and de Vocht (2011) have emphasized that requesting separate interviews could potentially generate anxiety within couples, as this approach might imply that secrets exist and that one person is willing to share these secrets with the researcher and not with his or her partner. Because of this concern, couples might be reluctant to participate in research where separate interviews are required.

4.4.2 Separate interviews performed simultaneously by different interviewers

This mode comprises all the previously mentioned advantages, plus the fact that the interviewer is not influenced by the other informant and that the interviewees may feel an additional safeguard of secrecy (Eisikovits & Koren, 2010; Forbat & Henderson, 2003). However, in addition to all the drawbacks mentioned previously, the difference between the two interviewers can be a problem, both at the time of data collection and later when analyzing the data, depending on how the analysis is performed. Eisikovits and Koren (2010) suggest choosing separate interviews performed simultaneously by different interviewers preferably when the two interviewers share similar world-views of the phenomenon under study.

4.4.3 Joint interviews

Joint interviews are generally preferred when it is central to the research that interactions be observed and analyzed. When participants are interviewed jointly, they present themselves not just as individuals but also as concurrent participants in a relationship (Taylor & de Vocht, 2011). The main advantage of joint interviews is to generate a joint picture and shared narrative, in addition to allowing the observation of some of the dynamics inherent to the relationship (Eisikovits & Koren, 2010). Participants can corroborate or supplement each other's stories: they can probe, correct, challenge, or introduce fresh themes for discussion that can result in further disclosure and richer data. Furthermore, joint interviews can result in particular insights that are not achievable with individual interviews as they provide a window into the dyad's world of shared experiences and meanings (Taylor & de Vocht, 2011). A joint interview will not produce an "average" at the two separate views of the members of the dyad, but another perspective that could not have been accessed by other means (Taylor & de Vocht, 2011). In addition, in joint interviews, as well as with focus groups, interactions between participants only become the focus of the analysis when determined by the research goal, but their influence on the data should still be acknowledged.

4.4.4 Separate and joint interviews with same or different participants

Interviewing both separately and jointly the same participants is perceived by Eisikovits and Koren (2010) as the best of both worlds. Taylor and de Vocht (2011) state that combining both individual and dyadic perspectives can result in a broader picture of the phenomenon and reveal more of its aspects. However, changes in audience might also impact on the version presented and might affect the benefits of both the separate and the joint interviews. In addition, questions remain as to whether the separate interviews or the joint ones should be conducted first and how. The order may have an impact on the data obtained. If the researcher chooses to begin with separate interviews, it can be difficult to address the same topics with both participants while maintaining confidentiality, unless the second interview is performed by a different interviewer. In contrast, if individual interviews are performed after a joint one, participants could have the tendency to stick to the discourse that was co-constructed in the joint interview. In addition to challenges to the interview process, both the analysis and the dissemination processes can become more complex, in the sense of deciding how to integrate the data obtained at both the individual and dyadic level. This could constitute an obstacle in a rigorous data analysis process.

Eisikovits and Koren (2010) suggest that this mode of interviewing could be appropriate when the topic is not so sensitive as to endanger participants' live and when analyzing interactions is inevitable in light of the study purpose. The option of conducting separate interviews with some participants and joint interviews with others can allow for comparisons, cross checking, and a form of triangulation, which can be interesting especially for post-positivist qualitative researchers, even if triangulation per se is possible only with larger samples (Eisikovits & Koren, 2010).

4.4.5 The challenge of protecting confidentiality while interviewing dyads

Regardless of the mode of data collection chosen (e.g., separate or joint interviews), what seems most important to us in order to maintain confidentiality is to consider each member of the dyad for him or herself and to try not to give any information to the other member of the dyad. For example, one participant could ask a questions such as "Did he or she tell you about. . . ?", but the researcher has to make sure that the interview material remains confidential, even if some form of information could be more difficult for the researcher to hide, such as being surprised for example. More challenging is dealing with information from one member about one aspect of the research question that the other member did not mention at all, and it happened on a few occasions in our study. However, there is also the need to clarify how the researcher and each member of the dyad are jointly responsible to protect confidentiality.

4.5 Returning transcripts to participants

The quality of transcription, in contrast to the quality of interviewing, is seldom addressed in the qualitative research literature (Kvale, 2007), and so is the practice of sharing transcript with interviewees. For Kvale (2007), an interview is "a live social interaction where the pace of the temporal unfolding, the tone of the voice and the bodily expression are immediately available to the participants in the face-to-face conversation, but they are not accessible to the out-of-context reader of the transcript" (p. 93), even when the reader is the person who was interviewed. For research participants, being presented with a typed version of false starts, pauses, and transcribed laughter might be experienced as startling or confrontational (Forbat & Henderson, 2005), as they are not used to these kind of written productions. Research participants are often not aware that their discourse encompasses numerous ungrammatical sentences. For Forbat and Henderson (2005), the decision to share transcripts with participants is often driven from feminist ideals of participant "ownership" of the transcription and empowerment through seeing the version to be used in analysis and publication. For us, the choice to share or not the transcripts with participants belongs with the researcher. Indeed, whereas in clinical practice the file belongs to the client (Canadian Psychological Association [CPA], 2000), in research, the collected data, which can take many forms, belong to the researcher, who can make the decision to either share it or not with the participants.

Following data collection, some researchers share transcripts with participants, and in the case of research involving dyads, Forbat and Henderson (2003) suggest that mailing each transcript back to the designated participant gives him or her the choice to share it or not with the other member of the dyad. In our case, as we had decided to only send transcripts on participants' demand and as no such request was made, we were not confronted with this particular aspect of the research process. We would encourage researchers who choose to share transcripts with their participants to consult them first before sending the transcripts, as having a printed version of their interview may pose a threat to confidentiality and make the transcript potentially more accessible to others. A thorough reflection on the purpose and reasons for this practice of sharing transcripts should be engaged in, especially when dyads are involved, to take into account the potential impacts of sharing on the protection of confidentiality (Forbat & Henderson, 2005).

4.6 Data analysis

Dyadic analyses are still in emergence in qualitative research, and few researchers have published on this way of analyzing data. For our research, the first author conducted separate interviews with both members of the dyad and data analysis for a dyad started only once a dyad was complete. In the absence of specific guidance on how to analyze on a dyadic level, analyzes were performed following the guidelines of interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009), beginning with the analysis of the data provided by the member of the dyad who had been interviewed first, followed by the analysis of the data provided by the other. After each participant's data had been analyzed individually, we mapped the dyadic data visually along the time-line of the transplant trajectory to get an idea of the parallel progression between the donor's and the recipient's experience of the living kidney donation. By doing so, we were able to identify overlap and contrast in our data, which allowed a global perspective that was more than the sum of the two individual versions (Eisikovits & Koren, 2010).

During this process, it is key for the researcher to keep on journaling his or her reflexive process regularly, as the biases mentioned earlier such as taking side or being influenced within the relationship, can creep up not only at the time of data collection but during data analysis as well. By being aware and reflecting upon these issues, they should not constitute an obstacle to a rigorous data analysis process.

If researchers choose to conduct joint interviews with both members of the dyad, the data analysis is likely to be similar to the way data from focus group are analyzed. The main disadvantage of this mode of data collection is that it does not allow for the development of individual versions of the relationship and reduces imbalance between versions because of partners being an audience to each other, thus reducing the material available for analysis (Eisikovits & Koren, 2010).

There are additional challenges to analyzing dyadic data when separate interviews are conducted by different interviewers. In such cases, analyses could be performed by the two interviewers, with the risk that each interviewer, having a more complete and comprehensive understanding of the perspective of the member of the dyad he or she interviewed, could take sides in favor of his or her member. An avenue that could help reduce this risk would be to have the data analyzed by a third researcher who did not conduct any of the interviews, but at the risk of losing precious non-verbal information that was observed during the interview. There are other challenges to consider when analyzing dyadic data when some participants were interviewed separately and others jointly, or if the study design included a joint and a separate interview for each research participant.

4.7 Results dissemination

Confidentiality is particularly salient during results dissemination when more than single individuals are interviewed, as the amount of data that could lead to identifying informants is (at least) doubled. Protecting internal confidentiality can become more challenging to achieve and additional care must be taken to ensure that details are rendered sufficiently anonymous to prevent either party from being exposed. If we presume that one member of the dyad recognizes his or her own words, it follows that the other member of the dyad's anonymity risks being broken. This loop in confidentiality is of particular relevance if members have not shared their transcripts or the content of their interviews with each other. This was definitively the main issue in our research. To lower the risk that participants would recognize themselves in our publications and therefore potentially learn facts about the other member of the dyad by association, we chose to publish our results on a general rather than dyadic level. Inevitably, this felt as though some interesting dyadic results and verbatims were not presented, but it allowed us to maintain an ethically defensible position.

What was particular to our study was that the type of relationship between members of the dyads was different across dyads (e.g., a parent donated to a child, a sister donated to her brother, etc), instead of the same (e.g., couples, teacher-student, etc.), and because the type of relationship was an important information, we could not easily disguise this relationship. Indeed, each participant was not only a donor or a recipient, he or she also fulfilled a social role toward the other member of the dyad that contributed to explaining his or her experience of the donation process. In contrast, in Eisikovits and Koren (2010)'s research about second couple-hood in old age, participants were all spouses, sharing the same type of relationship, which is potentially slightly less challenging to disguise. It seems easier to disguise part of the information in order to better protect internal confidentiality when dyads are similar and involve carer-caree, mentor-pupil, or parent-child.

4.8 Discussion

Qualitative research in an invaluable tool to providing us with the in-depth detailed description of some of the most intimate human experiences. It relies on a mode of data collection that is deeply personal and the nature of the relationship that develops between the researcher and the participants is particularly amenable to the disclosure of sensitive information (for example see Duncan, Drew, Hodgson, & Sawyer, 2009). When it comes to understanding the intimate experience of dyads, qualitative research allows us to collect data from two distinct but complementary perspectives that can be put together to derive a more complete picture of a given phenomenon and of the actions and decisions of two people involved can be influenced by one another's. In our case, conducting interviews with individuals who have shared the experience of a live kidney donation from both ends – as a donor or as a recipient – allowed us to derive a rich picture of how dyads go through the process of offering and accepting a kidney and their role relative to one another throughout the transplant trajectory (Ummel & Achille, 2015).

However, as we highlighted throughout the present article, many challenges arise when working with dyads, both in terms of the methodological decisions that have to be made at the time of the study design (e.g., recruiting members of dyads together or separately; interviewing together, separately or both; analyzing data individually or dyadically) and in terms of the threats to protecting material provided by one member of the dyad when that material was not meant to be shared with the other member (e.g., internal confidentiality) throughout the research process. What seems most important to us is to encourage researchers to reflect on those possible threats in advance to anticipate how they might affect each stage of the research, namely recruitment, the consenting process, data collection, returning transcripts to participants, data analysis and results dissemination. In our experience, our duty to protect confidentiality, especially internal confidentiality, came at the cost primarily of not being able to disseminate empirical results in as much details as we had initially hoped.

In addition to careful planning, we highly recommend keeping a journal and sharing a reflexive process, as it is impossible, in qualitative research, to predict all the potential issues that can arise (Duncan et al., 2009), even when a project was carefully reviewed by colleagues and institutional review boards. Qualitative researchers can aim to achieve the ideal research design, but the richness of researching near participants in their context remains a challenge as we also become dependent on that context and on all the surprises that can occur.

To conclude, it is particularly important in qualitative research to reflect on our research practice in terms of confidentiality, as given the inductive nature of qualitative research, our smaller sample size and our way of disseminating results by means of verbatim can make it more difficult to insure participants' protection of internal and external confidentiality. The methodological and ethical challenges are particularly relevant as research with dyads is increasingly emergent, especially in health-related contexts.

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CHAPITRE 5

DISCUSSION GÉNÉRALE

La présente thèse a poursuivi l'objectif général de mieux comprendre l'expérience de la transplantation d'organe de la perspective de dyades comprenant un donneur et un receveur d'une donation vivante de rein (DVR). Pour ce faire, nous avons réalisé un méta-résumé des études qualitatives qui avaient été publiées sur le sujet, puis nous avons réalisé une exploration en profondeur de l'expérience de donneurs et de receveurs d'une DVR, et ce en portant une attention particulière à leur trajectoire de transplantation et leurs enjeux relationnels. Enfin, suite à notre constat de la complexité de produire et publier des résultats d'une recherche qualitative impliquant des individus partageant une expérience commune, nous avons partagé nos pistes de réflexion et nos recommandations à cet égard.

Dans le premier article, nous avons tenté de réunir, par le biais de la méthode du méta-résumé, les recherches qualitatives portant sur l'expérience de donner et de recevoir un rein par donation vivante, et ce afin de dresser un portrait le plus complet possible du processus de donation tel qu'il avait été examiné à ce jour dans les écrits empiriques qualitatifs disponibles et mettre en lumière les aspects qui avaient encore peu été appréhendés par les chercheurs. Suite aux conclusions de ce premier article, notamment le constat du manque d'études empiriques considérant conjointement le donneur et le receveur d'une DVR au sein d'une même recherche, notre volet empirique a cherché à mieux comprendre l'expérience de dyades comprenant un donneur et un receveur d'une DVR, et en particulier les enjeux relationnels qui pouvaient s'exprimer dans ce contexte spécifique. Cette démarche qualitative et constructiviste s'est ancrée dans la tradition de l'analyse phénoménologique interprétative (IPA), et a fait l'objet du deuxième article. Dans le troisième article, nous avons présenté les enjeux méthodologiques et éthiques inhérents à la pratique de la recherche qualitative et du respect de la confidentialité des participants dans un contexte de dyades, soit d'individus partageant une expérience commune, sur la base des obstacles que nous n'avions pas anticipés et qui nous ont forcés à réfléchir au défi que pose la recherche qualitative impliquant plusieurs personnes se connaissant.

Dans le présent chapitre, nous revenons de façon succincte sur les conclusions de chacun des articles présentés, de manière à proposer des liens entre les différents contenus. Par la suite, nous présentons un portrait plus global du phénomène à l'étude, avant d'évoquer les implications pratiques et cliniques de la thèse. Nous discutons également des limites du travail effectué, et proposons des pistes qui pourraient servir de canevas pour des recherches ultérieures.

5.1 Synthèse et intégration des articles présentés

5.1.1 État des lieux sur l'expérience de donner et recevoir un rein par donation vivante

Par le biais de la méthode du méta-résumé proposée par Sandelowski et Barroso (2003, 2007), nous avons été en mesure de proposer un portrait global du processus de DVR tel qu'il peut être vécu par les donneurs et les receveurs, et ce en nous basant sur les écrits empiriques qualitatifs disponibles en 2010[1]. Suite à un travail rigoureux et systématique d'intégration, nous avons pu relever, de façon générale, que les recherches portant sur les donneurs étaient les plus nombreuses, et que la façon dont les donneurs faisaient l'expérience du processus de DVR était mieux documentée que l'expérience des receveurs. Considérant les implications inhérentes au

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[1] Soit au moment de la réalisation de cet article.

fait de donner un rein de son vivant, notamment passer de nombreux tests médicaux, subir une intervention chirurgicale sans bénéfice direct pour sa propre santé physique et perdre un rein, on peut comprendre que le processus de prise de décision de devenir un donneur vivant ait intéressé les premiers chercheurs dans le domaine, et que cela constitue un aspect présent dans la majorité des recherches décrivant l'expérience de la DVR. Un autre élément qui a rencontré un fort consensus parmi les recherches recensées est le fait que la plupart des donneurs n'expriment pas de regret par rapport à leur geste, et que souvent, il a été relevé que les donneurs réitéreraient leur geste si cela était possible et qu'ils avaient également retiré des bénéfices sur le plan personnel de leur expérience de DVR, une conclusion que l'on retrouve également dans plusieurs recherches quantitatives (Achille, Soos, Fortin, Pâquet, & Hébert, 2007; Johnson et al., 1999; Isotani et al., 2002; Ku, 2005; Fehrman-Ekholm et al., 2000; Jowsey & Schneekloth, 2008; Giessing et al., 2004). Cependant, les recherches résumées ont également permis de mettre en évidence des défis que les donneurs peuvent rencontrer dans le parcours de DVR, notamment les effets secondaires de l'intervention chirurgicale, comme la douleur, les nausées et la fatigue, auxquelles certains donneurs disaient ne pas avoir été adéquatement préparés. Le parcours de DVR a également le potentiel d'être accompagné de difficultés émotionnelles et psychologiques lorsque les résultats de la transplantation ne sont pas positifs pour le receveur.

Parmi les quinze recherches synthétisées dans le cadre de notre premier article, seules six comprenaient, notamment, des receveurs, ce qui nous donne une perspective plus limitée de leur expérience. De façon générale, leur expérience de la DVR était décrite de façon positive, mais plusieurs chercheurs ont relevé la présence d'ambivalence dans leur processus, notamment relativement à leur volonté de communiquer leur besoin d'un greffon rénal ou de demander à un ou une proche de leur donner un rein. Une fois qu'un rein leur était proposé, les receveurs passaient généralement par une période de réflexion avant d'accepter, et cette période de réflexion variait d'un receveur à un autre. La plupart du temps, après la transplantation, les receveurs rapportaient une amélioration significative de leur état de santé, et étaient généralement reconnaissants envers leur donneur. Cependant, certains auteurs ont relevé que plusieurs receveurs pouvaient ressentir des pressions psychologiques, soit en regard à la nécessité de prendre de façon assidue et continue une médication immuno-suppressive parfois considérée comme contraignante, soit dans le contexte de dynamiques relationnelles particulières entre le donneur et le receveur de certaines dyades.

Relativement aux enjeux relationnels, bien que peu d'études les aient répertoriés de façon systématique et détaillée, il est souvent mentionné que la relation entre le donneur et le receveur reste la même, s'améliore, ou que les deux protagonistes disent s'être rapprochés suite à la greffe. Cependant, des études révèlent également des cas moins nombreux où des relations se sont détériorées à cause de conflits entre le donneur et le receveur, à cause de problèmes et de tensions en lien avec la transplantation, ou dans des cas où la relation était déjà difficile avant la transplantation.

Sur la base de ces constats, nous avons choisi d'approfondir les enjeux relationnels pouvant exister entre le donneur et le receveur d'une DVR par le biais d'une analyse phénoménologique interprétative (IPA) de dyades ayant fait l'expérience d'une DVR. En effet, cela nous a permis de proposer un complément de données à l'expérience des receveurs, qui n'ont pas reçu à ce jour l'attention de recherche dont ils pourraient bénéficier, mais également de la comprendre en interaction avec l'expérience des donneurs par le biais de notre considération de dyades en interaction. C’est ce que nous avons proposé dans notre deuxième article.

5.1.2 Trajectoire de transplantation et expérience relationnelle des dyades donneur-receveur

Les résultats du deuxième article proposent un portrait de la trajectoire de transplantation, soit (a) l’expérience de la maladie du receveur, (b) l’expérience d’offrir et d’accepter un rein, (c) la période des tests, (d) la transplantation d’organe à proprement parler et finalement (e) la période post-transplantation, telle qu’elle peut être vécue par des dyades en interaction, ainsi que l’expérience relationnelle vécue par les donneurs et les receveurs. Ainsi, pour les participants que nous avons rencontrés, comme cela avait également été relevé dans les écrits scientifiques antérieurs (notamment Clemens et al., 2006; Ummel, Achille, & Mekkelholt, 2011), la DVR constitue, tant pour les donneurs que pour les receveurs, une expérience éminemment positive. Pour les receveurs, parce que cela a changé leur vie, et pour les donneurs, parce que cet acte est associé à une réalisation personnelle ainsi qu’à la satisfaction de constater chez le receveur une amélioration de la santé et de la qualité de vie à laquelle ils ont directement et concrètement contribuée.

Bien que les données recueillies proviennent de dyades de donneurs et de receveurs de DVR et qu’elles aient été analysées par dyade, la majorité des thèmes et des résultats présentés dans le deuxième article sont divisées entre l’expérience des donneurs et l’expérience des receveurs, et les résultats à un niveau dyadique ne sont pas abordés. En effet, l’apport de présenter de façon dyadique la trajectoire des cinq dyades ne nous semblait pas valoir le risque de compromettre la confidentialité interne des participants à la recherche qui auraient pu se reconnaître et ainsi en apprendre sur l’expérience de l’autre membre de leur dyade, comme cela a été abordé dans le troisième article. Comme la prise de conscience de cet enjeu éthique nous a mené à cesser de recruter d'autres dyades, les données dyadiques à notre disposition nous permettent principalement d'avoir une compréhension interactionnelle et relationnelle de l'expérience de donner et de celle de recevoir. En effet, sur le plan dyadique, la diversification interne obtenue en termes de types de relation entre le donneur et le receveur ne nous a pas permis d'obtenir une saturation de nos données et nos analyses et résultats à cet égard restent préliminaires.

Un apport particulièrement significatif de l'analyse et de l'interprétation de nos données est la mise en relief que le processus de transplantation était mieux compris lorsque l'on considérait le contexte social et interpersonnel plus large dans lequel évoluait chaque dyade donneur-receveur, et ainsi, nous avons proposé que la décision de donner ou d'accepter un rein peut être appréhendée comme un prolongement du rôle social auquel la personne adhère par rapport à autrui dans sa vie quotidienne. En nous inspirant d'écrits en psychologie sociale, nous avons considéré les rôles sociaux définis par des devoirs, des normes et des attentes, qui, lorsqu'ils sont cohérents avec les valeurs et les actions de l'individu, vont faire en sorte qu'il les réalise et ressente un sentiment d'efficacité dans son rôle social (Bettencourt & Sheldon, 2001). La réalisation d'un rôle social a été associée à la satisfaction de trois besoins psychologiques de base : l'autonomie, le fait d'être en lien avec autrui[2] et la compétence (Bettencourt, Molix, Talley, & Sheldon, 2006; Talley, Kocum, Schlegel, Molix, & Bettencourt, 2012). Nous avons alors suggéré que lorsque les donneurs ou les receveurs avaient une expérience positive et satisfaisante de la DVR, notamment dans les cas de relation génétique, c'est lorsque le donneur ou le receveur, par son choix de donner ou d'accepter le greffon rénal, agissait en cohérence avec son rôle social, ce

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[2] Traduction personnelle de l'original anglais "relatedness".

qui lui permettait de se sentir autonome, en lien avec autrui et compétent. C’est notamment ce que nous avons pu retrouver dans les cas où un parent a effectué un don à un enfant adulte et dans les deux cas de donation au sein de la fratrie. Dans la dyade de relation de travail, n’ayant pas de rôle ou de repère social clair, la satisfaction des besoins de base n’était pas toujours atteinte et qu’il devenait aussi ardu de donner un sens au geste même de donner ou d’accepter un rein. Dans le cas de la dyade de donation entre conjoints, même si chaque conjoint a décrit, après la transplantation, l’expérience de transplantation comme un événement très positif, la période de pré-transplantation a été décrite comme une période particulièrement éprouvante, à différents égards, par chaque conjoint. En outre, il y a plusieurs particularités inhérentes à une dyade de conjoints. Tout d’abord, l’évolution de la maladie du receveur a été vécue au quotidien par le donneur, qui était conscient des implications concrètes, par exemple les nombreuses restrictions alimentaires et qui devait également s’y adapter. Dans une relation génétique, peu importe la qualité de la relation, le lien génétique perdure dans le temps (un frère restera toujours un frère). Dans le cas des couples, le contexte conjugal peut évoluer, et une personne pourrait se retrouver à avoir reçu ou donné un rein d’un ex-conjoint, ce qui peut amener des complications importantes. Dans la dyade qui a participé à l’étude, les conjoints étaient mariés depuis une vingtaine d’années, avaient deux enfants jeunes adultes, et le sens attibué au geste du don variait entre les conjoints. Pour le receveur, cela devenait inconcevable pour lui d’être en processus de recevoir un rein du donneur lorsqu’il avait des conflits conjugaux avec ce dernier, alors que pour le donneur, cette fluctuation dans l’acceptation du rein offert était particulièrement éprouvante, puisque le sens attribué au don était une preuve d’amour, comme un renouveau des voeux maritaux après la vingtaine d’années de vie commune. Ainsi, il s’agit de souligner que les interprétations sur la façon dont le rôle social de conjoint peut tenter l'expérience de donner ou de recevoir doivent être appréhendées avec prudence puisqu'elles ne proviennent de l'étude que d'une seule dyade, et à cet égard, l'étude de différentes dyades de conjoints devrait permettre une compréhension plus approfondie et complète de leur expérience relationnelle de la DVR.

Cependant, il est important de noter que ces résultats ont été obtenus par le biais d'un échantillon de donneurs et de receveurs caucasiens et francophones, vivant en Amérique du Nord, et que l'interprétation des rôles sociaux en lien avec le geste de donner et de recevoir ne serait peut-être pas adéquate pour d'autres contextes culturels. En effet, même si la procédure biomédicale de la transplantation d'organe est relativement pareille dans toutes les sociétés, la façon dont ces enjeux sont adressés et compris varie entre les cultures et les sociétés (Arie, 2008), par exemple au niveau de la façon de déterminer la mort, afin de pouvoir prélever un organe pour une donation cadavérique. Le sens du devoir et les obligations relationnelles associées aux rôles sociaux et familiaux sont ainsi susceptibles de varier d'une culture à une autre, et c'est la raison pour laquelle nous suggérons que chaque milieu de transplantation doit être à l'affût du contexte dans lequel il évolue, et notamment des variations et des minorités qui peuvent être présentes dans une culture donnée. Il est à noter que notre échantillon était composé des dyades francophones caucasiennes adhérant à des rôles sociaux assez clairs, et que ce n'est vraisemblablement pas le cas de toutes les dyades qui traversent le processus de DVR dans la clinique de transplantation où s'est déroulée l'étude. Des auteurs hollandais se sont intéressés aux différences pouvant exister entre les ressortissants des cultures européenne et non-européenne en termes de pratique de la transplantation d'organe. En analysant des données sur une période de 7 ans, ils ont constaté qu'aux Pays-Bas, les receveurs d'origine non-européenne avaient statistiquement moins de chances de se présenter à la clinique prétransplantation avec un donneur potentiel que la composition de la liste d'attente et la population générale, et que ces donneurs potentiels étaient moins susceptibles de donner (Roodnat et al., 2010). Ces mêmes auteurs ont également relevé des différences dans les types de relations qui effectuent une DVR : les ressortissants non-européens reçoivent moins souvent un organe d'un conjoint, mais plus souvent d'un membre de la fratrie. Il s'agit donc de rester attentif aux différences culturelles, puisque l'expérience décrite peut être vécue différemment par des candidats à la donation vivante provenant d'une culture différente.

Des enjeux relationnels et culturels sont également susceptibles d'apparaître dans des configurations relationnelles où un parent donne un organe à un jeune enfant ou à l'inverse, dans le cas où un enfant adulte donne un rein à un parent, mais nous n'avons pas eu la chance de recruter ces types de dyades au sein de notre recherche empirique. Cependant, ces particularités commencent à être investiguées dans les écrits scientifiques. Par exemple, une étude récente, menée au Royaume-Uni, a exploré si les parents donneurs se sentaient forcés de donneur un rein à leur enfant, et si le choix de donner un organe à son propre enfant malade pouvait réellement être considéré comme une décision volontaire (Burnell, Hulton, & Draper, 2015). Des cas de "dépression paradoxale" ont également été relevés au Japon après qu'un parent ait donné un rein à un enfant, et ce en l'absence de toute complication que ce soit pour le donneur ou le receveur (Fukunishi et al., 1998). Certains auteurs ont également relevé que des adolescents ayant reçu un organe de leur parent démontraient une faible capacité de gestion de leur maladie et/ou une santé mentale sous-optimale après la donation vivante (Aujoulat, Schwering, & Reding, 2012). En effet, lors de la période de la pré-adolescence, alors que le receveur tend à se différencier de ses parents, cela peut constituer un défi d'avoir en soi le greffon rénal d'un parent (Baines, Beattie, Murphy, & Jindal, 2001).

Nous avons également remarqué que les donneurs rapportaient différentes raisons et motivations relativement à leur choix de donner un rein, ce que nous n'avions pas trouvé dans les écrits scientifiques rencontrés sur le processus de prise de décision des donneurs. Nous avons proposé que le sens de donner est complexe et multiple, et que même s'il peut être compris dans un contexte social et interpersonnel plus large, il retient un caractère hautement personnel et individuel. Plusieurs donneurs ont insisté sur le fait qu'il s'agissait de leur propre choix de donner, et ont mis en évidence une composante d'intérêt personnel propre dans cette décision, ce qui rejoint la perspective de Glannon et Friedman Ross (2002), qui postulent que les relations génétiques impliquent des obligations morales, comme celle de donner un rein si on est en mesure de le faire. Cela nous a amené à nous questionner sur la composante d'altruisme que l'on peut retrouver ou non selon différents auteurs en DVR. Nous abondons encore dans le sens de Glannon et Friedman Ross (2002), en postulant que dans les relations génétiques ou émotionnelles, ce ne serait pas l'altruisme qui inciterait les donneurs à poser ce geste, mais plutôt un sens du devoir qu'ils doivent et veulent absolument remplir de sorte à améliorer l'état de santé de la personne avec laquelle ils partagent un lien particulier, et ainsi de jouer un rôle actif et cohérent avec leurs obligations sociales. Il est intéressant de noter que cette motivation à vouloir améliorer la santé du receveur se retrouve également chez les donneurs de moëlle osseuse (Garcia et al., 2013). Ces auteurs ont également relevé que dans les cas de donation dans la fratrie, les donneurs se trouvaient souvent forcés par devoir moral de sauver la vie de leur frère ou de leur soeur. Dans le cas de la donation entre collègues, la relation ne comportait pas d'obligations sociales ou de devoirs clairs, et en ce sens, on pourrait se trouver plus proche d'une dynamique que l'on retrouve davantage dans les cas de donation altruiste.

Nous avons également considéré nos données à la lumière de la théorie du don de Marcel Mauss (1950/2012), qui décrivait la présence de trois obligations interreliées : donner, recevoir et rendre. Les donneurs rencontrés ressentaient du soulagement ou de la fierté d'avoir pu remplir leur obligation de donner, alors que l'obligation de recevoir était plus délicate à combler pour les receveurs, qui ont tous eu comme premier réflexe de refuser le greffon rénal qui leur était proposé. C'est seulement après un certain laps de temps, un moment de réflexion, et parfois la réitération de l'offre par leur donneur, qu'ils ont finalement accepté la donation vivante. Nous suggérons donc que leur seule alternative étant la dialyse, les receveurs n'ont en réalité pas un réel choix de recevoir, mais peuvent effectivement se sentir dans un sens obligés de recevoir. En regard de la troisième obligation, celle de rendre, dans les relations génétiques et émotionnelles, les donneurs ont indiqué clairement leur souhait de ne rien recevoir en échange de leur geste, même si certains ajoutaient par ailleurs avoir reçu la médaille du courage ou un cadeau de la part de leur receveur, et les receveurs n'ont pas exprimé de sentiment d'endettement moral ou psychologique ou de redevance envers leur donneur. En revanche, dans la relation impliquant des collègues, l'obligation ressentie de rendre au donneur était beaucoup plus présente, surtout que le donneur n'était prêt à recevoir aucune gratitude de la part du receveur, ce qui a contribué à rendre extrêmement difficile pour le receveur la signification qu'il pouvait accorder au greffon rénal reçu et au geste posé par son donneur. L'incomplétude du cycle ou de la spirale du don dans ce dernier exemple semble avoir complexifié le sens accordé au geste de DVR, et ainsi la réciprocité n'était plus atteinte dans la relation.

5.1.3 Enjeux entourant la confidentialité en recherche qualitative avec des dyades

Dans le troisième article, les enjeux particuliers de la pratique de la recherche qualitative impliquant des dyades ont été abordés, en particulier selon l'angle du défi que représente le respect de la confidentialité des données des participants lorsqu'ils se connaissent, et sont susceptibles de se reconnaître dans les résultats de recherche publiés. En effet, comme c'est un défi que nous avons rencontré lors de la publication des résultats empiriques et des analyses dyadiques qui avaient été complétées, sur la base des écrits scientifiques disponibles en la matière, nous avons proposé des pistes de réflexion et de recommandations pour la pratique de la recherche qualitative avec des dyades, et ce en suivant le cours chronologique habituel d'un devis de recherche, soit (a) le recrutement, (b) le consentement à participer, (c) la collecte de données, (d) la validation des transcriptions par les participants, (e) l'analyse de données, et (f) la dissémination des résultats. Chaque étape du processus de recherche a été abordée en présentant d'une part les recommandations et expériences disponibles dans les publications de recherches, mais également en utilisant notre propre expérience empirique pour soulever des questionnements qui ne sont encore que peu présents dans les écrits scientifiques actuels, comme les enjeux inhérents à l'analyse des données dyades et à la dissémination de ces résultats. Ces suggestions et recommandations pourront, nous l'espérons, contribuer à une réflexion plus large de la communauté qualitative sur les enjeux entourant la réalisation rigoureuse et responsable en termes de confidentialité de recherches qualitatives impliquant des dyades.

5.2 Implications pratiques : intervention auprès des candidats à la DVR

En réalisant une rare incursion dans l'expérience de dyades donneur-receveur en contexte de DVR, nous avons pu mettre en évidence à quel point le type de relation qu'entretiennent le donneur et le receveur ainsi que leur rôle social et leurs obligations relationnelles inhérentes à leur type de relation a un impact significatif dans leur façon de vivre leur expérience de la donation vivante. En ce sens, l'expérience de donner, et d'accepter un rein, est facilitée lorsqu'elle est cohérente avec le rôle social endossé par l'individu, ce qui permet à trois besoins psychologiques de base d'être remplis : l'autonomie, le fait d'être en lien avec autrui et la compétence. Cette mise en relief de l'importance du rôle social et du contexte interpersonnel plus large dans lequel évoluent les dyades de DVR permet une meilleure compréhension de la trajectoire à travers laquelle évoluent les donneurs et les receveurs de DVR, et fournit également un cadre pour mieux comprendre les enjeux relationnels pouvant survenir au sein des dyades. Cette nouvelle connaissance peut être pertinente dans l'information que l'on fournit aux candidats à la DVR, de sorte qu'ils aient des attentes les plus réalistes possibles en regard du processus à venir et puissent ainsi avoir un consentement libre et éclairé dans leur prise de décision.

Plusieurs conclusions auraient également le bénéfice d'être transmises aux équipes qui interviennent auprès de donneurs et receveurs potentiels de DVR. Par exemple, le fait que les receveurs passent souvent par une période de réflexion relativement à l'acceptation du greffon rénal, voire même par un refus initial, peut être important à considérer pour les équipes qui pourront ainsi informer les candidats à la donation que les receveurs ont souvent besoin d'un moment de réflexion, voire même parfois que l'on leur réitère l'offre à quelques reprises, avant d'être en mesure d'accepter un tel geste. Il s'agit ainsi de comprendre les enjeux rencontrés tant par les donneurs que par les receveurs à ce moment du processus, et d'accompagner chaque membre de la dyade de la façon la plus appropriée, compte tenu de notre meilleure compréhension de leur expérience de la trajectoire de DVR.

Enfin, lorsque la relation entre le donneur et le receveur comporte certains défis, ou que les rôles sociaux partagés par chaque membre de la dyade ne constituent pas des repères sociaux clairs, on peut s'attendre à ce qu'il soit plus difficile pour le donneur ou le receveur de donner un sens au processus de DVR, et certains enjeux tels que l'expression de la gratitude ou le sentiment de redevance, ou encore l'absence de réciprocité, sont davantage susceptibles de survenir. Dans ce cas, un accompagnement plus attentif de l'équipe soignante peut être à recommander.

5.3 Contributions de la présente thèse

Dans la première partie de la thèse, par le biais de la méthode du méta-résumé, nous avons été en mesure de présenter de façon synthétisée et systématique les conclusions de quinze recherches qualitatives. Alors que les méta-analyses, qui permettent de compiler les résultats des études quantitatives, sont de plus en plus courantes, l'agrégation au sein d'un même travail des résultats de recherches qualitatives sont encore moins répandues, quoi que tout autant indispensables. En effet, alors que la recherche qualitative est souvent critiquée pour sa forte dépendance au contexte dans lequel la collecte de données a été effectuée, et que son potentiel de transférabilité est moins élevé que la recherche quantitative, la méthode du méta-résumé présente l'avantage d'intégrer et de nuancer les résultats d'études ayant été réalisées dans plusieurs contextes, auprès de participants différents, et parfois selon des philosophies de recherche variées, permettant ainsi de mettre en évidence ce qui peut se rapprocher de l'essence de l'expérience du phénomène à l'étude, mais en conservant toutes ses nuances. Nous espérons que cette expérience positive et riche pourra contribuer à nourrir l'intérêt des chercheurs qualitatifs à recenser de façon plus systématique les écrits issus de la tradition qualitative.

Tout au long de notre processus de recherche, nous avons eu l'intention de "mieux comprendre" l'expérience des donneurs et des receveurs de DVR, que ce soit par le biais des écrits déjà publiés ou par le biais de leur propre discours. Ainsi, l'objectif de notre devis de recherche n'était pas de corréler les concepts ou encore de mettre en évidence des relations de causalité. Nous avons plutôt situé notre devis de recherche dans une démarche heuristique, et c'est là une grande partie de sa contribution, c'est-à-dire sa capacité d'approfondir et de susciter des réflexions, autant que de nouvelles pistes d'investigation autour de la question de la donation vivante.

Ainsi, cette thèse contribue à l'avancement des connaissances, puisqu'elle offre en premier lieu une contribution approfondie de l'expérience de la DVR telle qu'elle a été appréhendée par les écrits qualitatifs publiés (premier article) ainsi que par la façon dont des dyades de donneurs et de receveurs peuvent en faire l'expérience (deuxième article). En second lieu, la thèse contribue également à l'avancement de la recherche qualitative auprès des dyades en rapportant les défis rencontrés par ce type de méthodologie ainsi qu'en formulant des pistes de réflexion et des recommandations (troisième article).

En considérant conjointement les donneurs et les receveurs d'une DVR dans une même étude, et par le choix d'une démarche qualitative et interprétative, l'interprétation psychologique de l'expérience de la DVR est proposée selon une perspective dynamique et interactionnelle, ce qui constitue une valeur ajoutée par rapport aux écrits actuels sur la DVR, puisque les receveurs et les dyades sont encore sous-représentés (Clemens et al., 2006; Ummel et al., 2011). Enfin, la mise à profit des obstacles rencontrés dans l'analyse et la dissémination des résultats de l'étude de dyades contribue également à l'originalité de la présente thèse.

5.4 Limites

Bien que la présente thèse propose une contribution significative à différents égards, tel que nous l'avons abordé ci-dessus, nous souhaitons que les conclusions soient considérées avec prudence, notamment en reconnaissant les limites inhérentes à certains choix méthodologiques.

Tout d'abord, de par notre choix de concevoir la recherche dans un paradigme constructiviste-interprétatif, les analyses et les interprétations que nous avons présentées ont pu émerger grâce à un rigoureux travail de co-construction entre les participants rencontrés, la candidate et sa directrice de recherche. Si les mêmes participants avaient été rencontrés par une autre chercheuse, ou que les données recueillies avaient été analysées par d'autres personnes, il est indéniable que les conclusions obtenues auraient différé. Nous souhaitons relever ici que la démarche interprétative à laquelle nous avons abouti est riche de notre contribution rigoureuse et systématique, mais également subjective des données recueillies, puisque notre démarche était teintée d'une part par notre formation en psychologie clinique et de la santé, mais également par certaines de nos caractéristiques personnelles.

Ensuite, étant donné la complexité de rencontrer les donneurs et les receveurs avant l'opération de transplantation, nous avons choisi de récolter nos données uniquement après la greffe, ce qui engendre un possible biais rétrospectif, puisque l'ensemble de la trajectoire de transplantation que nous décrivons provient du discours des donneurs et des receveurs une fois la totalité du processus complété. De ce fait, il serait extrêmement intéressant de rencontrer des donneurs et des receveurs à plusieurs étapes de leur processus de transplantation.

Nos données ont également été collectées au sein d'une seule clinique de transplantation, comprenant une culture et une façon de procéder inhérente à l'établissement et aux professionnels de la santé qui y travaillent, ce qui peut limiter la diversification de l'expérience de la DVR. En effet, dans le cadre de notre méta-résumé, nous avons pu constater que les pratiques cliniques pouvaient varier d'un établissement à l'autre et d'un pays à l'autre, et il est évident que nos données sont teintées par la pratique clinique de la clinique de transplantation d'où nous avons recruté nos participants.

5.5 Pistes de recherche futures

D'autres avenues de recherche pourraient permettre de poursuivre l'objectif de compréhension de la DVR que nous avons entamé dans la présente thèse. Par exemple, il serait judicieux d'enrichir la compréhension actuelle par un devis de recherche longitudinal qui inclurait plusieurs entretiens de recherche avant et après la transplantation d'organe, ainsi qu'une combinaison d'entretiens de recherche individuels et conjoints, de sorte à faciliter la prise en compte de la dynamique relationnelle au sein de la dyade et la dissémination des résultats relatifs à la perspective dyadique. Des données ethnographiques, incluant notamment des entretiens avec des membres de l'équipe soignante, ainsi que de l'observation participante systématique dans la clinique de transplantation, auraient également le potentiel d'illustrer la dynamique relationnelle entre le donneur et le receveur, mais également avec les membres de l'équipe de soin. Dans le cas où des données ethnographiques seraient recueillies, la possibilité d'inclure des dyades de plusieurs cliniques de transplantation pourrait être envisagée, ce afin de mettre en évidence de potentielles différences entre les pratiques et cultures des milieux de soin par rapport à la donation spécifiquement.

Enfin, si nous avons recherché à diversifier au maximum les types de relations entre les donneurs et les receveurs, nous nous sommes retrouvés avec une large majorité de femmes qui ont donné, ce qui reflète une certaine réalité en greffe rénale où plus de femmes donnent et plus d'hommes reçoivent (Achille et al., 2007), et une majorité de relations génétiques. Une plus grande diversification des types de relation aurait le potentiel d'éclairer encore davantage l'influence du rôle social dans le processus de transplantation, et c'est une recommandation que nous aimerions formuler pour de futures recherches. Il serait en particulier intéressant d'intégrer des dyades comprenant un enfant adulte qui aurait donné un rein à son père ou à sa mère. En effet, certains écrits mettent en relief les enjeux particuliers au don d'un parent à un enfant, don qui renverse la hiérarchie générationnelle propre à plusieurs cultures.

5.6 Conclusion

La démarche de recherche entreprise nous permet de suggérer que le rôle social et le contexte interpersonnel plus large dans lequel évoluent le donneur et le receveur d'une dyade de DVR permet de donner un certain sens à ce geste, et permet de l'inscrire dans l'expérience plus large de vie des personnes concernées. Nous avons relevé que lorsque les rôles sociaux sont clairement définis et que les individus y adhèrent, ils pouvaient plus facilement faire sens de l'expérience de donner ou de recevoir un rein par DVR, alors qu'à l'inverse, le manque de repère social clair pouvait générer une plus grande incompréhension et une intégration psychique plus ardue du geste de DVR, ainsi que certaines ambiguïtés dans la dynamique relationnelle. Cette compréhension plus large de la trajectoire et des enjeux relationnels en contexte de DVR a le potentiel d'outiller davantage les équipes soignantes dans leurs interventions auprès des candidats à la DVR. D'autres recherches sont inévitablement requises pour explorer davantage ces constats.

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Annexe I

I.1 Grilles d'entrevue

Objectifs de recherche

Mieux comprendre l'expérience vécue de la relation entre le donneur et le receveur d'une donation vivante de rein.

Principes

Établissement de quelques questions générales et assez large, puis "boîte à outils" de questions de relance. Dans le courant de l'entretien, rester attentive aux thèmes abordés et identifier les notions sur lesquelles rebondir, sous la forme de reflets ou de relances. L'important étant de les ramener à leur propre expérience de la relation.

Présuppositions personnelles et issues des écrits scientifiques

- une donation vivante d'organe peut être lue avec la perspective de la théorie du don de Marcel Mauss (donner => recevoir => rendre)
- une meilleure compréhension du rôle de la relation dans la donation vivante d'organe est fondamentale, notamment en regard du développement en cours de la donation croisée.
- L'être humain est touché par les évènements et la maladie qui survient à un-e proche et a envie de l'aider, selon différentes possibilités, dont la donation vivante d'organe.

Protocole d'entretien

Commencer par quelques questions simples, pour faciliter le contact, dans le genre : comment est-ce que vous êtes venu jusqu'ici ? Où est-ce que vous habitez ?

- Parler spontanément des intérêts ou des questionnements qui ont amené au choix d'en faire une thèse de doctorat en psychologie.
- Présenter le formulaire de consentement, demander s'il y a des questions, signer, puis expliquer l'existence de l'enregistrement et sa raison (justesse des propos).
- Les éléments que l'on va aborder peuvent être abstraits : c'est normal.
- Je ne connais pas le sujet, je n'ai pas d'attentes, donc il n'y a pas de bonne ou de mauvaise réponse, c'est vraiment votre expérience personnelle qui m'intéresse.
- Il arrive souvent qu'en cours d'entretien, des éléments inattendus vous viennent en tête, et vous ne savez pas vraiment pourquoi, si ça vous vient à l'esprit, c'est probablement que c'est relié au sujet d'une manière ou d'une autre.
- Il y a peut-être des questions qui vont vous paraître évidentes, mais cela m'intéresse d'avoir votre réponse dans vos propres mots.
- Les questions que je vais vous poser sont larges, et peuvent aborder tous les éléments que vous souhaitez ainsi que les détails que vous êtes à l'aise de partager.
- L'idée est que l'entretien soit davantage une discussion qu'un interrogatoire !
- Est-ce que vous avez des questions avant que l'on commence ?

Début de l'enregistrement

I.1.1 Version donneur

Racontez-moi… comment en êtes-vous venu à donner un rein à un de vos proches ?

Comment est-ce que vous vous sentiez par rapport à [receveur] ? Avant ? Pendant ? Après ?

Avez-vous remarqué des différences ? Si non, comment ? Si oui, comment ?

Comment pensez-vous que [le receveur] a vécu cette expérience de la donation ?

Est-ce que vous avez quelque chose à ajouter, quelque chose que l'on aurait oublié d'aborder ?

Comment avez-vous vécu le moment de discussion que l'on vient d'avoir ensemble ?

I.1.2 Version receveur

Racontez-moi… comment en êtes-vous venu à recevoir un rein d'un donneur vivant ?

Comment est-ce que vous vous sentiez par rapport à [donneur] ? Avant ? Pendant ? Après ?

Avez-vous remarqué des différences ? Si non, comment ? Si oui, comment ?

Comment pensez-vous que [le donneur] a vécu cette expérience de la donation ?

Est-ce que vous avez quelque chose à ajouter, quelque chose que l'on aurait oublié d'aborder ?

Comment avez-vous vécu le moment de discussion que l'on vient d'avoir ensemble ?

Annexe II

II.1 Fiches signalétiques

II.1.1 Version donneur

II.1.1.1 Profil socio-démographique

1. Sexe : ....

2. Date de naissance : ....

3. Langue maternelle : ....

4. Pays d'origine : ....

   Si autre pays que Canada, en quelle année êtes-vous arrivé au Canada ? ....

5. Niveau d'éducation plus élevé complété :

   ( ) Primaire incomplet

   ( ) Primaire

   ( ) Secondaire

   ( ) Collégial ou équivalent

   ( ) Baccalauréat

   ( ) Maîtrise

   ( ) Doctorat

( ) Autre : ....

6. État civil :

   ( ) Célibataire

   ( ) Célibataire, mais en relation

   ( ) Marié-e, depuis ....

   ( ) Conjoint-e de fait depuis ....

   ( ) Divorcé-e

   ( ) Divorcé-e, mais dans une nouvelle relation

   ( ) Veuf/ve

   ( ) veuf/ve, mais dans une nouvelle relation

7. Votre état civil a-t-il changé depuis la donation vivante de rein ? ....

8. Combien avez-vous d'enfant ? ....

9. Avec qui vivez-vous (conjoint, enfants, etc.) ? ....

10. Quelle est votre occupation ? ....

11. Statut d'emploi :

    ( ) Travailleur/se à temps plein

    ( ) Travailleur/se à temps partiel

    ( ) Présentement sans emploi

( ) Présentement en arrêt de travail

( ) Au foyer

( ) Retraité-e

( ) Étudiant-e

( ) Autre : ....

12. Votre statut d'emploi a-t-il changé depuis la donation vivante de rein ? Si oui, quel a été le changement ? ....

II.1.1.2 Profil médical

1. Date de la donation vivante de rein : ....
2. Temps écoulé depuis la donation vivante de rein : ....
3. Lien avec le receveur : ....
4. Type de lien : ....
5. Maladie / diagnostic du receveur : ....
6. Date du diagnostic : ....

II.1.2 Version receveur

II.1.2.1 Profil socio-démographique

1. Sexe : ....

2. Date de naissance : ....

3. Langue maternelle : ....

4. Pays d'origine : ....

   Si autre pays que Canada, en quelle année êtes-vous arrivé au Canada ? ....

5. Niveau d'éducation plus élevé complété :

   ( ) Primaire incomplet

   ( ) Primaire

   ( ) Secondaire

   ( ) Collégial ou équivalent

   ( ) Baccalauréat

   ( ) Maîtrise

   ( ) Doctorat

   ( ) Autre : ....

6. État civil :

   ( ) Célibataire

( ) Célibataire, mais en relation

( ) Marié-e, depuis ....

( ) Conjoint-e de fait depuis ....

( ) Divorcé-e

( ) Divorcé-e, mais dans une nouvelle relation

( ) Veuf/ve

( ) veuf/ve, mais dans une nouvelle relation

7. Votre état civil a-t-il changé depuis la transplantation rénale ? ....

8. Combien avez-vous d'enfant ? ....

9. Avec qui vivez-vous (conjoint, enfants, etc.) ? ....

10. Quelle est votre occupation ? ....

11. Statut d'emploi :

( ) Travailleur/se à temps plein

( ) Travailleur/se à temps partiel

( ) Présentement sans emploi

( ) Présentement en arrêt de travail

( ) Au foyer

( ) Retraité-e

( ) Étudiant-e

( ) Autre : ....

12. Votre statut d'emploi a-t-il changé depuis la transplantation réanle ? Si oui, quel a été le changement ? ....

II.1.2.2 Profil médical

1. Date de la transplantation rénale : ....
2. Temps écoulé depuis la transplantation rénale : ....
3. Lien avec le donneur : ....
4. Type de lien : ....
5. Maladie / diagnostic : ....
6. Date du diagnostic : ....

Annexe III

III.1 Notes réflexives après entretien

1. **Circonstances de l'entretien**

   Heure :

   Lieu :

2. **Conditions de production du discours**

3. **Mentions particulières par rapport aux conditions de vie, s'il y a lieu**

4. Observation du participant en entrevue et déroulement de l'entrevue

5. Impressions personnelles

6. Remarques méthodologiques

7. Synthèse descriptive de l'entretien

Annexe IV

IV.1 Lettres de recrutement

IV.1.1 Donneurs

CHUM

COMITÉ D'ÉTHIQUE DE LA RECHERCHE
DU CHUM
DATE 2009/05/18
SIGNÉ [redacted]
APPROUVÉ

Invitation à participer à une recherche sur la donation vivante de rein

Madame, Monsieur,

La présente lettre vous est adressée parce que vous avez récemment donné un rein à un proche. Une étude est présentement en cours à la Clinique de Transplantation Multi-Organes de l'Hôpital Notre-Dame ; elle vise à mieux comprendre les impacts relationnels entre le donneur et le receveur d'une donation vivante de rein. Comme vous avez vous-même été donneur, vous pourriez nous être d'une grande aide en partageant avec nous votre expérience de la donation vivante.

Dans le cas où vous seriez intéressé à participer, votre participation consisterait à prendre part à une entrevue d'une durée approximative de 60 à 90 minutes. L'entrevue serait menée par Deborah Ummel, étudiante au doctorat en psychologie à l'Université de Montréal. L'entrevue se déroulerait, suivant votre préférence, à l'Hôpital Notre-Dame, à votre domicile ou dans tout autre endroit de votre choix.

Les informations récoltées grâce à cette étude, autant les aspects positifs que les difficultés que vous avez peut-être rencontrées, permettront d'outiller l'équipe soignante afin qu'elle intervienne efficacement auprès de patients concernés par une donation vivante.

Afin de manifester votre intérêt par rapport à l'étude, nous vous invitons à remplir la fiche ci-jointe et à la faire parvenir à la chercheure principale Deborah Ummel, dans l'enveloppe pré-adressée et pré-affranchie ci-jointe. En cas de réponse positive, elle vous contactera par téléphone pour vous expliquer l'étude. Pour toute question concernant l'étude, veuillez vous adresser à Deborah Ummel, chercheure principale, au (514) 343-6111 poste 1-4594.

Nous vous remercions de votre attention,

[redacted]

Michel R. Pâquet, M.D., Ph.D.
Service de néphrologie
Équipe de transplantation rénale
Hôpital Notre-Dame du CHUM
1560, rue Sherbrooke Est
Montréal, (Québec) H2L 4M1
Tél. (514) 890-8000 ext. 26616

CENTRE HOSPITALIER DE L'UNIVERSITÉ DE MONTRÉAL

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HÔPITAL SAINT-LUC
1058, rue Saint-Denis
Montréal (Québec)
H2X 3J4

****COUPON-REPONSE À RETOURNER****

ÉTUDE DE L'IMPACT D'UNE DONATION VIVANTE DE REIN SUR LA RELATION ENTRE LE DONNEUR ET LE RECEVEUR

COMITÉ D'ÉTHIQUE DE LA RECHERCHE DU CHUM
DATE 2009/05/05
SIGNÉ [redacted]
APPROUVÉ

Chercheure principale : Deborah Ummel, M.Sc. Étudiante au Ph.D.,
Département de psychologie, Université de Montréal

Sous la direction de : Marie Achille, Ph.D. Professeure agrégée,
Département de psychologie, Université de Montréal
Psychologue, Équipe de transplantation, CHUM

En collaboration avec l'équipe de transplantation du CHUM

Merci d'entourer la réponse qui vous correspond :

- *J'accepte que Deborah Ummel me contacte dans le cadre de son étude sur l'expérience de la donation vivante de rein afin de me parler davantage de son étude et de fixer un rendez-vous avec moi pour une entrevue.*
- *Je ne suis pas intéressé-e par l'étude sur l'expérience de la donation vivante de rein, merci de ne pas me contacter.*

Nom : ____

Numéro(s) de téléphone : Maison : (____) ______________________

Travail : (____) ______________________

Cellulaire : (____) ______________________

Adresse :

____

____

____

____

Lieu et date de la transplantation rénale : ______________________

Lien avec le receveur (ex : mon frère) **:** ______________________

IV.1.2 Receveurs

CHUM

COMITÉ D'ÉTHIQUE DE LA RECHERCHE
DU CHUM
DATE 2009/05/05
SIG [redacted]
APPROUVÉ

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[redacted]

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ÉTUDE DE L'IMPACT D'UNE DONATION VIVANTE DE REIN SUR LA RELATION ENTRE LE DONNEUR ET LE RECEVEUR

COMITÉ D'ÉTHIQUE DE LA RECHERCHE DU CHUM
DATE 2009/05/05
SIGNÉ [redacted]
APPROUVÉ

<u>Chercheure principale</u> : Deborah Ummel, M.Sc. Étudiante au Ph.D.,
Département de psychologie, Université de Montréal

<u>Sous la direction de</u> : Marie Achille, Ph.D. Professeure agrégée,
Département de psychologie, Université de Montréal
Psychologue, Équipe de transplantation, CHUM

<u>En collaboration avec</u> l'équipe de transplantation du CHUM

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Nom : ____

Numéro(s) de téléphone : Maison : (____) ______________________

Travail : (____) ______________________

Cellulaire : (____) ______________________

Adresse :

____

____

____

____

Lieu et date de la transplantation rénale : ______________________

Lien avec le donneur (ex : mon frère) **:** _________________________

Annexe V

V.1 Formulaire de consentement

CHUM

COMITÉ D'ÉTHIQUE DE LA RECHERCHE DU CHUM
DATE 2009/05/05
SIGNÉ [redacted]
APPROUVÉ

ÉTUDE DE L'IMPACT D'UNE DONATION VIVANTE DE REIN SUR LA RELATION ENTRE LE DONNEUR ET LE RECEVEUR

Chercheure principale : Deborah Ummel, M.Sc. Étudiante au Ph.D.,
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Sous la direction de : Marie Achille, Ph.D. Professeure agrégée,
Département de psychologie, Université de Montréal
Psychologue, Équipe de transplantation, CHUM

En collaboration avec l'équipe de transplantation du CHUM

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

PARTIE 1 : INFORMATION

1. PRÉAMBULE

Nous sollicitons votre participation à un projet de recherche sur la donation vivante de rein. Avant d'accepter de participer, veuillez prendre le temps de lire et de comprendre les renseignements qui suivent. Nous vous invitons à poser toutes les questions que vous jugez utiles au chercheur responsable du projet ou à ses associés et à leur demander de vous expliquer tout mot ou renseignement qui n'est pas clair.

2. NATURE ET OBJECTIFS DU PROJET DE RECHERCHE

Le but de cette recherche est de mieux comprendre la manière dont les donneurs et les receveurs d'une donation vivante de rein vivent le processus de transplantation, et comment la relation qu'ils entretiennent se trouve éventuellement modifiée. Des études antérieures ont en effet relevé que fréquemment, l'acte de donation de rein modifie la relation entre le donneur et le receveur. Les deux personnes peuvent être encore plus proche qu'avant l'intervention, ou à l'inverse, certaines difficultés peuvent apparaître.

Cette étude cherche à comprendre plus en profondeur ce que vivent concrètement les donneurs et les receveurs après la donation. Les résultats de cette étude permettront de recueillir des informations qui serviront à aider de futurs patients lors de leur expérience de donation vivante.

Si on vous a sollicité pour participer à cette recherche, c'est que vous remplissez les conditions suivantes :

- Vous êtes âgé de plus de 18 ans
- Vous parlez et comprenez suffisamment le français pour participer à une entrevue
- Vous avez donné ou reçu un rein (donation vivante)

Ce projet recrutera entre 20 et 30 patients au service de néphrologie de l'Hôpital Notre-Dame du CHUM.

3. DÉROULEMENT DU PROJET DE RECHERCHE

La participation à l'étude implique de prendre part à une entrevue enregistrée sur audiocassette, portant sur votre expérience de la donation vivante, notamment sur les aspects positifs de ce processus, mais également sur les difficultés que vous avez pu rencontrer. Vous serez interviewé seul-e par la chercheuse principale. L'entrevue sera d'une durée approximative de 60 à 90 minutes et aura lieu soit à l'Hôpital Notre-Dame, soit dans un autre lieu à votre convenance.

4. INCONVÉNIENTS ASSOCIÉS AU PROJET DE RECHERCHE

Il se peut que la discussion de l'expérience de transplantation réanime chez vous des émotions négatives comme la tristesse. Cependant, on ne s'attend pas à ce que ces réactions dépassent ce que vous avez connu durant votre parcours de transplantation rénale. De plus, si vous le souhaitez, un suivi pourra être effectué par un psychologue du CHUM ou par un psychologue dans la communauté identifié par l'équipe responsable du projet en collaboration avec vous.

5. AVANTAGES

Il se peut que vous retiriez un bénéfice personnel de votre participation à ce projet de recherche, mais on ne peut vous l'assurer. Par ailleurs, les résultats obtenus contribueront à l'avancement des connaissances dans le domaine de la transplantation et permettront de mettre en place des interventions dont pourront bénéficier de futurs patients.

6. PARTICIPATION VOLONTAIRE ET POSSIBILITÉ DE RETRAIT

Votre participation à ce projet est volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner de raisons, en faisant connaître votre décision au chercheur responsable du projet ou à l'un des membres du personnel affecté au projet.

Votre décision de ne pas participer à ce projet de recherche ou de vous en retirer n'aura aucune conséquence sur la qualité des soins et des services auxquels vous avez droit et sur votre relation avec votre médecin ou les autres intervenants. Advenant que vous vous retiriez du projet, l'information recueillie à votre sujet sera détruite.

7. CONFIDENTIALITÉ

Durant votre participation à ce projet, le chercheur responsable ainsi que son personnel recueilleront et consigneront dans un dossier de recherche les renseignements vous concernant. Seuls les renseignements nécessaires pour répondre aux objectifs scientifiques de ce projet seront recueillis. Ces renseignements comprendront les informations recueillies lors de votre entrevue.

Tous les renseignements recueillis demeureront strictement confidentiels dans les limites prévues par la loi. Afin de préserver votre identité et la confidentialité des renseignements, vous ne serez identifiés que par un numéro de code. La clé du code reliant votre nom à votre dossier de recherche sera conservée par le chercheur responsable.

Le chercheur responsable du projet utilisera les données à des fins de recherche dans le but de répondre aux objectifs scientifiques du projet décrits dans le formulaire d'information et de consentement. Ces données seront conservées cinq ans par la chercheure responsable. Les enregistrements audio et les données transcrites seront détruites après ce délai.
Les données pourront être publiées dans des revues spécialisées ou faire l'objet de discussions scientifiques, mais il ne sera pas possible de vous identifier.

À des fins de surveillance et de contrôle, votre dossier de recherche, s'il y a lieu, pourra être consulté par une personne mandatée par le comité d'éthique de la recherche du CHUM à des fins de surveillance du projet. Cette personne adhère à une politique de confidentialité.

À des fins de protection, notamment afin de pouvoir communiquer avec vous rapidement, vos noms et prénoms, vos coordonnées et dates de début et de fin de votre participation au projet seront conservés pendant un an après la fin du projet dans un répertoire à part maintenu par le chercheur responsable ou par l'établissement.

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis, et les faire rectifier au besoin, et ce, aussi longtemps que le chercheur responsable du projet ou l'établissement détiennent ces informations. Cependant, afin de préserver l'intégrité scientifique du projet, vous pourriez n'avoir accès à certains de ces informations qu'une fois votre participation terminée.

8. COMPENSATION

Il n'y a pas de compensation monétaire prévue pour la participation à ce projet. Tous les participants pourront recevoir un résumé écrit des résultats une fois le projet complété.

9. IDENTIFICATION DES PERSONNES-RESSOURCES.

Si vous avez des questions concernant le projet de recherche ou si vous éprouvez un problème que vous croyez relatif à votre participation au projet de recherche, vous pouvez communiquer avec la chercheuse principale du projet de recherche, Deborah Ummel, au numéro suivant : (514) 343-6111, poste 1-4594.

Pour toute question concernant vos droits en tant que sujet participant à ce projet de recherche ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec le commissaire local aux plaintes et à la qualité des services de l'Hôpital Notre-Dame, Madame Céline Roy, au numéro suivant : (514) 890-8000, poste 26047.

10. SURVEILLANCE DES ASPECTS ÉTHIQUES DU PROJET DE RECHERCHE

Le comité d'éthique de la recherche du CHUM Notre-Dame a approuvé ce projet de recherche et en assure le suivi. De plus, il approuvera au préalable toute révision ou toute modification apportée au formulaire d'information et de consentement et au protocole de recherche.

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

PARTIE 2 : CONSENTEMENT

J'ai pris connaissance du formulaire d'information et de consentement. Je reconnais qu'on m'a expliqué le projet, qu'on a répondu à mes question et qu'on m'a laissé le temps voulu pour prendre une décision.

Je consens à participer à ce projet de recherche aux conditions qui y sont énoncées. Une copie signée et datée du présent formulaire d'information et de consentement m'a été remise.

Une copie du formulaire d'information et de consentement sera également déposée dans mon dossier médical. En conséquence, je comprends que cette information sera disponible à toute personne ou compagnie à laquelle je donnerai accès à mon dossier médical.

Nom et signature du sujet de recherche Date

Signature de la personne qui a obtenu le consentement si différent du chercheur responsable du projet de recherche.

J'ai expliqué au sujet de recherche les termes du présent formulaire d'information et de consentement et j'ai répondu aux questions qu'il m'a posées.

Nom et signature de la personne qui obtient le consentement Date