THE EXPERIENCE OF DONATING AND RECEIVING A KIDNEY: A SYSTEMATIC REVIEW OF QUALITATIVE STUDIES

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SUMMARY

Background: The experiences described by people who have undergone kidney transplant are complex. Understanding how donors and recipients experience kidney transplantation can help us to design strategies that provide a more person-centred health care.

Objectives: To review articles that report the experiences of donors and recipients in the living-donor kidney transplantation process.

Method: A systematic review of qualitative studies was carried out. PubMed, Scopus, Web of Science, CINAHL and PsycINFO databases were used to search for articles published in English, French and Spanish between 2005 and 2018.

Results: Twenty-nine articles were included in this review. For recipients, receiving a kidney is a positive experience (positive feelings and significant experience) that also involves certain difficulties and stressors (making a difficult decision, fears and worries). The experience of the donors is positive as they are motivated to improve the life of the recipient. They are committed to donating and use coping strategies as well as experiencing personal growth. On the contrary, being a donor involves certain difficulties and stressors (personal investment, mental, physical and economic impact and overcoming opposition) and a perception of deficiency in the health system (lack of information and attentiveness).

Conclusion: Donating and receiving a kidney is a positive experience that involves certain difficulties and a variety of stressors for both the donors and recipients. Moreover, the donors note deficiencies in the health system.

KEY WORDS Kidney recipient • Transplantation • Lived experience • Living donor • Systematic review •

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INTRODUCTION

Living-donor kidney transplantation is the best treatment option for patients with end-stage renal disease. Data show that survival of both the patient and the graft of the living donor is higher when compared with the kidney transplant from a deceased donor (Collaborative Transplant Study 2019). Moreover, living donation helps palliate the problem of scarcity of organs that exists in many countries (Matas & Delmonico 2012). Nearly, 40.2% of kidney transplantations carried out globally are from living donors (WHO 2016).

There are a number of benefits associated with transplantation for donors and recipients, such as quality of life, satisfaction and well-being (Clemens *et al.* 2006; Landreneau *et al.* 2010; WHO 2016; Klop *et al.* 2018), but at the same time arise economic and psychosocial problems, problems of medical monitoring, feelings of indebtedness and family conflict (Waterman *et al.* 2006; Jacobs *et al.* 2015; Ralph *et al.* 2017; De Pascuale *et al.* 2018; Kisch *et al.* 2018; Ruck *et al.* 2018).

The experience of donation has been of great interest to qualitative research, and there have been several reviews of the motivations of donors, their expectations and the consequences of donating (Clarke *et al.* 2006; Tong *et al.* 2012a; Kisch *et al.* 2018). However, the experience of the recipient in living-donor kidney transplantation has received less attention in the literature. In one qualitative meta summary (Ummel *et al.* 2011), only one study that reported on the experiences of the recipients was found. In the review led by Hanson *et al.* (2015) on the decision of recipients to undergo living donor transplantation, there is a greater presence of the experience of renal patients; and in the review carried out by the team of Ralph *et al.* (2017), the relationship between the donor and recipient in the context of kidney donation is addressed.

The aim of this systematic review is to update the evidence of qualitative studies that report the experiences of both donors and recipients of kidneys in order to gain greater understanding of the significance of transplantation and to understand what the process of donating and receiving a kidney involves.

Qualitative research can provide valuable information on the impact of the illness in the individual's life and their lived experience. Robust qualitative publications can help professionals and policymakers to make progress and improve the treatment and results of transplantation (Tong *et al.* 2013).

METHOD

To answer the research question ("How are the experiences of donors and recipients in the living-donor kidney transplantation process?"), a systematic review (SR) was undertaken applying PRISMA statement (Moher *et al.* 2015). PICo framework was used to guide the review focus (Munn *et al.* 2018):

- Population: Donors and recipients of the kidney.
- Phenomenology of Interest: Experiences of undergoing kidney transplantation.
- Context: Not commercial renal transplantation.

INCLUSION CRITERIA

Studies that included donors and/or kidney recipients over 18 years old and that focused on the experience of the living-donor kidney transplantation before, during and after the transplant. Only primary studies that used qualitative methods were included. The use of interviews, focus groups and observations to gather data was taken into consideration. Studies on deceased-donor kidney transplantation and those where the kidney transplant was carried out for financial/commercial gain were excluded.

SEARCH STRATEGY

A full search strategy combining different key terms (see Table 1) was conducted to find the primary studies published on the topic of interest. Five electronic databases were used: PubMed, Scopus, Web of Science, CINAHL and PsycINFO. The search was limited to studies in English, French and Spanish published between 1 January 2005 and 31 December 2018. This period was chosen because in 2005 there was a reduction in living donor transplants after years of continuous increase, surpassing deceased-donor transplants since 2000 (OPTN 2007; Wolfe *et al.* 2009). There are some countries that in response to this situation activate plans to encourage even more living donations.

• Kidney transplantation/kidney transplant/renal transplantation/live kidney transplantation/live kidney transplant
• Kidney receptor/kidney recipient/living kidney donor/live donor/living donor
• Illness experience/illness perception/lived experience/narration

Table 1: Search terms.

INCLUSION AND ASSESSMENT PROCESS

The review process is illustrated in Figure 1. Once the database search had been completed and the duplicates removed, the studies by title and/or abstract were selected based on the inclusion criteria. The PDFs of the selected studies were retrieved, and three authors analysed both the complete text and the methodological quality independently.

To assess the quality of the evidence, the Critical Appraisal Skills Programme (CASP) (Taylor *et al.* 2000; Singh 2013) was used. This tool is accessible at: https://casp-uk.net/casp-tools-checklists/. CASP qualitative checklist consists of 10 questions with three possible answers: Yes, No and Can't Tell. We gave 1 point to the Yes answers and 0 to the No and Can't Tell answers. The studies that score more than seven points were included. Two authors (LR and EO) reviewed each selected study independently, and if there was lack of agreement it was settled through discussion with a third reviewer (EM). As a result of the assessment process, seven studies were deemed to be of low quality and were excluded from the review (see Supplementary Table S1).

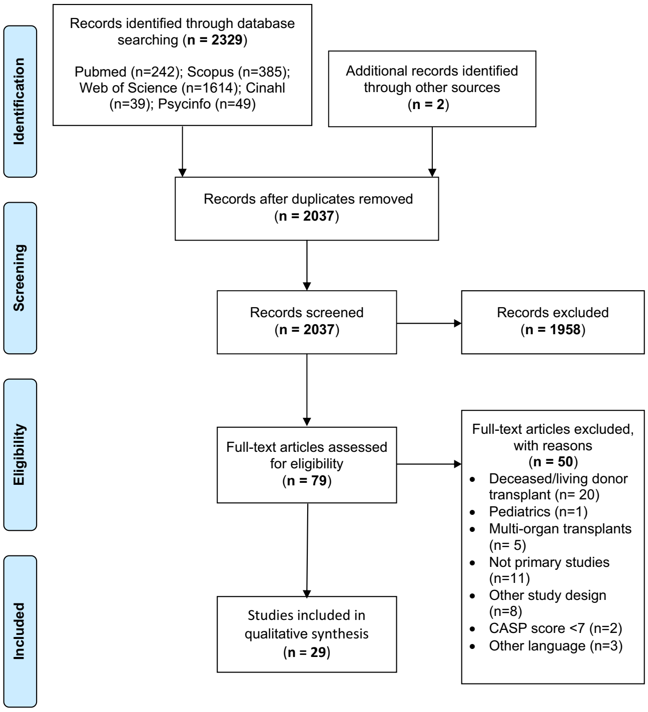

Figure 1: PRISMA flow diagram, Moher et al. *(2009).*

DATA EXTRACTION AND SYNTHESIS

Data from the studies that fulfilled the criteria were extracted using the data extraction table (Table 2). Two authors extracted the data independently and subsequently shared it with the group of reviewers. For data synthesis process we followed the guidelines for systematic reviews of qualitative evidence of the Joanna Briggs Institute (2017). The qualitative data of each study was identified in the form of findings from the repeated reading of the text. Each finding was categorised and arranged into subthemes and then into themes based on the similarity of meaning (see Supplementary Table S2). One author did the initial coding (LR); and the categorising into subthemes and themes was carried out in consensus with the other reviewers (EO and MH).

RESULTS

RESULTS OF THE SEARCH

The results of the search (Figure 1) identified 2,331 study records. A large number of articles were excluded (n = 1,958). Among the 79 studies selected for full-text appraisal, 50 studies were excluded. Of these, 20 were studies of deceased-donor kidney transplants (KT) or failed to differentiate the results of living and deceased donations; 1 was in the field of paediatrics; 5 involved multi-organ transplants; 11 were not primary studies; 8 used a method that was not qualitative; 2 had a CASP score under seven; and 3 were published in a language other than English, French or Spanish.

CHARACTERISTICS OF THE INCLUDED STUDIES

The studies included in the review use qualitative methods. In Table 3 we identify the research design of each study as stated by the actual authors. Nine different countries were represented in the included studies, and the total number of participants was 580, 477 of whom were donors and 103 recipients. Twenty-two studies used a sample of donors alone, two studies of just recipients and in five studies the participants were couples of donors and recipients. The studies explore the lived experiences of the donors and recipients in the assessment and pre-transplantation phase, the immediate post-operative phase, and in the short- and long-term after the transplant (see Supplementary Table S3).

RESULTS

Table 3 provides a summary of the results for each study. Since most of the studies analysed the experiences of the donors (D) and recipients (R) separately, we present their results

• Title	• Source	• Data Collection
• Authors	• Purpose	• Outcomes
• Date of publication	• Study design	• Conclusions
• Country	• Sample	• Limitations

Table 2: Data extraction.

accordingly. Following Joanna Briggs Institute guidelines (2017), we classified studies findings on donors into 11 categories that were synthesised into three themes, and the studies on recipients into four categories that were synthesised into two themes (see Supplementary Table S2). The first two themes that emerged as experiences of the kidney transplant of both donors and recipients are the same, but they are related to different characteristics that we will now discuss. The third theme is exclusive to donors.

RESULTS OF THE STUDIES IN DONORS

The experience of kidney donors is shown to be a positive one, both before and after the donation, although it involves certain difficulties and stressors and a perception of deficiency in the health system.

THEME DI: DONATION AS A POSITIVE EXPERIENCE

D1.1. MOTIVATION TO IMPROVE THE LIFE OF THE RECIPIENT

Most of the studies on donors show that they donate their kidney to improve the life of the recipients. Their concern for the health of the recipient and their desire to improve their quality of life, alleviate complications and even delay death are key reasons that drive them to be donors (Andersen *et al.* 2005; McGrath *et al.* 2012; Farahani *et al.* 2016; Ummel & Achille 2016; Meyer *et al.* 2017). Most of the donors featured in the studies are family members that have witnessed the recipient's diminishing quality of life. Some have seen them go through dialysis and wish to mitigate the impact of their illness and see the need for transplantation (Brown *et al.* 2008; Adams-Leander 2011). Altruistic, or non-directed, kidney donors, like related or non-related donors (Bertelsen *et al.* 2015), wish to offer greater life chances and help others (Tong *et al.* 2012b; Challenor & Watts 2014).

Some donors explain that they have seen the life of the recipient improve after the kidney transplant (Andersen *et al.* 2007; Gill & Lowes 2008; Williams *et al.* 2009).

D1.2. DONATE WITH CONVICTION

The decision to donate a kidney is made by the donors themselves; it is they who offer to donate with conviction and resolve. The decision-making process tends to be easy and spontaneous (Andersen *et al.* 2005; McGrath *et al.* 2012). Confidence of the donors in their own health is important when it comes to deciding to donate (Manera *et al.* 2017). There is not a desire to keep the body intact so the preservation of the integrity of the body does not influence the donor's decision. After the donation, the donors do not experience grief for the donated organ (Andersen *et al.* 2005; Williams *et al.* 2009; Ummel & Achille 2016). The donors do not expect to receive anything in return from the recipient and do not consider their donation to be a heroic or an extraordinary act (Gill & Lowes 2008; McGrath *et al.* 2012; Davis *et al.* 2017). The decision to donate to people one knows is coherent and is well-integrated within the family system (Ummel & Achille 2016).

D1.3. COPING STRATEGIES

The practical and mental preparations help to cope with the donation. During the assessment period there is the hope to be accepted as a donor (Agerskov *et al.* 2015, 2018). Confidence in the transplant success rate, in the health system and health professionals helps to cope with the donation. The donors state that not thinking about the risks of the donation to themselves or the possible rejection of the organ in the recipient helps them during the transplant process (Hanson *et al.* 2017). The donors are more concerned about the health of the recipient than their own health (Adams-Leander 2011), even the non-directed donors (Tong *et al.* 2012b).

Searching for information, comparing previous surgical experiences and organising the family and working life of the donors before the surgical intervention helps them to cope with less stress. Support from the family (Manera *et al.* 2017) and health professionals (Agerskov *et al.* 2016; Hanson *et al*. 2017), as well as religious and spiritual beliefs are important to help cope with the fears of donating (Maghen *et al.* 2018).

D1.4. PERSONAL GROWTH

The experience of donating a kidney provides personal benefits. Feelings of joy and pride feed a feeling of self-realisation and self-esteem. In the immediate post-operative phase, the donor already feels personal satisfaction (Gill & Lowes 2008; Gill 2012; Bertelsen *et al.* 2015), which lasts over time (Andersen *et al.* 2007). This leads them to say that they would donate again (Williams *et al.*

Author(s), year, country	Objective	Study design	Sample	Key results
Adams-Leander (2011) USA	To provide a general picture of the experience of African-American living kidney donors	Qualitative, Phenomenology, Interview	8 Living kidney donors	The donors received support from the family and religious community They are afraid for the health of the recipient and see the need for transplant There are economic costs for the donor and an investment of time The donors trusted the health professionals but lacked sufficient information Feelings of pride in being able to donate Depression in the recovery period as they are unable to do the same activities as before Not afraid about their own long-term health
Agerskov *et al.* (2015) Denmark	To explore the living kidney donors' experiences during the donor assessment process	Qualitative, Phenomenology, Observation and semi-structured interview	16 Potential living kidney donors	During the assessment process the donors are hopeful about being accepted They feel more worried about the health of the recipient than about their own health Communication and dialogue with the health professionals gives the donor a positive feeling and one of control and not confusion and frustration
Agerskov *et al.* (2016) Denmark	To investigate the donors' experiences of donation and their recovery period, in the first three months after donation	Qualitative, Phenomenology, Open interview	8 Living kidney donors	The donors prepare for the donation practically and mentally They experience unexpected post-operative problems (nausea, pain) The donors state that the information, support and care of the health professionals is important The donors experience a feeling of union and protection towards the recipient Support from the family during recovery is important, but it can also occasionally be a burden After the donation there is a feeling of joy for the recipient. Donors have never regretted the decision to donate, but they have "had doubts about their kidney function"
Agerskov *et al.* (2018) Denmark	To investigate the experiences and considerations on becoming, and during the process of being, a living kidney donor	Qualitative, Phenomenology, Interviews and Participant observation	19 Potential living kidney donors	The potential donors are driven to donate so as to help the recipient, and they express some concern about their own health The potential donors hope to be accepted and show frustration when they are rejected The donors talk of positive changes in their lives after the donation Fear and uncertainty arise when there are complications after the donation The donors showed confidence in their decision and did not regret the donation after the transplantation They consider dialogue and support from the health professionals essential
Andersen *et al.* (2005), Norway	To explore the physical and psychosocial issues related to the experiences of living	Qualitative, Phenomenology, In-depth interviews	12 Living kidney donors	The decision to donate is spontaneous, with no doubts and to improve the health of another person They use coping strategies to deal with the new, unknown situation

(Continues)

TABLE 3 (Continued)

Author(s), year, country	Objective	Study design	Sample	Key results
	kidney donors one week after open donor nephrectomy			The surgical intervention is painful and the post-operative phase is unpleasant The donor–recipient relationship is strengthened The donor is concerned about the recovery of the recipient and not so much for his/her own health after the operation The donation is a significant act for the donor
Andersen *et al.* (2007), Norway	To explore the experiences regarding physical and psychosocial health during the first year after donor surgery	Qualitative, Phenomenology, Semi-structured interview and In-depth interview	12 Living kidney donors	One year later the donor experiences pride, a rise in self-esteem, personal growth and recognition from the family The relationship with the recipient remains warm and close Exhaustion and lack of energy was longer than expected. Mild depression Unsatisfied expectations with respect to the medical follow-up. Mental stress of returning to the role they had before donation Negative feelings after failure of the transplant
Bertelsen *et al.* (2015) Denmark	To explore how the recipients and living donors experienced the first three post-operative days after kidney transplantation	Qualitative, Phenomenological-hermeneutic, Semi-structured interview	14 Living kidney donors and 14 recipients	Giving and receiving a kidney is a significant experience for donors and recipients. Donors experience satisfaction for helping a relative. For the recipients, receiving a kidney is a huge gift The donors and recipients experienced post-operative discomfort The participants were happy to be in hospital together (calm, ease in recovery) The donors did not express concern for their own health, but did for the post-operative recovery of the recipient and the possible failure of the transplant The donors and the recipients have different post-operative needs
Brown *et al.* (2008), Canada	To 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	Qualitative, Phenomenology, Semi-structured interview	12 Living kidney donors	They decided to donate in order to mitigate the impact of the disease; they witnessed the haemodialyses treatment of the recipients They have no doubts about donating The donors are well-informed before the donation The donors had to tolerate changes in visits or the operation of the health system The donors valued being close to the recipients in the post-operative phase They showed trust in the health professionals They felt cared for and supported during the assessment period and the operative phase
Challenor & Watts (2014), England	To explore how prospective altruistic kidney donors construct their decision to donate	Qualitative, In-depth interview	6 Altruistic kidney donors	Three themes emerged with respect to the decision to donate: (a) Oriented towards others (help others); (b) Rational and risk-related (donation as a safe procedure); and (c) Self-oriented (donation as a source of emotional gain and increase in self-esteem) The donors experienced opposition to their decision to donate altruistically from family members and friends The donors did not need or wish to maintain their body intact
Clarke *et al.* (2014) England	To understand the motivations of UK donors and their	Qualitative, Grounded Theory, Interview	14 UK donors (unspecified	The altruistic donors' experience of donation is satisfactory and does not involve lasting psychosocial concerns Fear of disapproval by the family or other people in the community

(Continues)

TABLE 3 (Continued)

Author(s), year, country	Objective	Study design	Sample	Key results
	experience during the donation process		kidney donation)	The recipient's recognition strengthens positive feelings without breaking the anonymity Altruistic donors experience a feeling of personal well-being after the donation
Cuesta-Briand *et al.* (2015) Australia	To explore the experiences of potential living kidney donors before the transplantation	Qualitative, Phenomenology, In-depth interview	19 Living kidney donors	There are direct and indirect costs associated with the assessment to be a donor The assessment process lacks flexibility to adapt to personal and work circumstances Unrealistic expectations about the side effects of the operation and recovery time Concern about the financial impact after the donation
Davis *et al.* (2017) USA	To identify barriers and coping mechanisms that black live kidney donors and recipients experienced while receiving or donating a kidney	Qualitative, Semi-structured interview	14 Recipients and 6 living kidney donors	The recipients denied or minimised the severity of their illness and this delayed or impeded the search for a donor Family and faith were sources of support for the recipients The donors experienced others' opposition and the recipients' resistance as obstacles to the donation Donating a kidney to their recipient is seen as normal by the donors and not as something extraordinary The donors received information and support from the health professionals
Farahani *et al.* (2016), Iran	To explore factors affecting Iranian family donors' motivation for kidney donation	Qualitative, Descriptive, Semi-structured interview	14 Living kidney donors	The motives of the living donors are: (a) Feelings of love and responsibility (close relationship with the recipient and fear for his/her health); (b) Spiritual motives (personal spiritual satisfaction); and c) Better benefits for the recipient and not harmful for the donor
Farahani *et al.* (2016b), Iran	To explore the outcomes of kidney donation in living-related donors in Iran	Qualitative, Descriptive, Semi-structured interview	16 Living kidney donors	The donation provides results: (1) Individual (new life opportunities, personal satisfaction and spiritual opportunities); and (2) Family (strengthening of family bonds and gratitude and respect of the family towards the donor)
Ghahramani *et al.* (2014), USA	To explore different perceptions of rural and urban patients with chronic kidney disease (CKD) about kidney transplantation	Qualitative, Focus group	23 Patients with chronic kidney disease	Both rural and urban patients recognised "independence" as a major advantage of transplantation. For the urban group, the freedom to travel and increased life expectancy were also major advantages The two groups identified the tedious pre-transplant testing and work expenses as an obstacle to the transplantation For the rural group, the distance to the transplant centre made the transplant assessment difficult The two groups expressed feelings of gratitude towards the donor. In the rural group there was also concern for the donor The urban group preferred an anonymous donor due to unease about "a sense of life-long indebtedness"
Gill & Lowes (2008), England	To gain a theoretical understanding of the live transplantation	Qualitative, Phenomenology,	11 Donor–recipient dyads	Regarding donors' experiences:

(Continues)

TABLE 3 (Continued)

Author(s), year, country	Objective	Study design	Sample	Key results
	experience from the perspectives of donors and recipients	Semi-structured interview		They offer to donate to improve the well-being of the recipient. Making the decision is easy and is taken confidently They had some post-operative discomfort (nausea and pain) They are glad to see the benefits for the recipient and experience personal satisfaction Donors tended to downplay their actions and do not want anything in return Regarding the recipients' experiences: They do not accept the offer of the kidney straight away out of concern for the donor's health The transplantation has a positive impact (returning to work, going on a holiday, etc.) They are very grateful towards the donor The donor–recipient relationship is the same after the transplantation, perhaps even better
Gill (2012), England	To explore donor and recipient experiences of stressors and coping mechanisms associated with live-related renal transplantation.	Qualitative, Phenomenology, Semi-structured interview	11 Donor–recipient dyads	The decision to donate is voluntary, fast and simple for the donors, and difficult to accept for the recipients For the participants the transplant represented hope and optimism, but there were also worries about the surgery and post-operative pain The biggest stressors for the recipients were concern for the donor and fear of organ rejection Support between donor and recipient and being positive and resolute were used as coping mechanisms The donors felt they were poorly attended to in the follow-up after the donation
Halverson *et al.* (2018), USA	To examine the attitudes to living donation from donors who themselves subsequently developed end-stage renal disease (ESRD)	Qualitative, Semi-structured interview	20 Living kidney donors (those who had developed CKD and had no medical insurance)	The donors that later developed ESRD described their decision to donate as an obvious and natural one within the family system and without having received any pressure from the recipient or the rest of the family The donors that developed ESRD would donate again, but they refuse to receive a kidney from a relative in order not to expose them to the same risks they went through
Hanson *et al.* (2017), Australia and Canada	To describe donors' experiences of the evaluation process	Qualitative, Grounded theory, Focus group	123 Living kidney donors	For the donors, the health of the recipient was primary Trust in the donor's own health and in the health system They minimise the risks to their own health Overcoming the resistance of the recipients, family and religious community was difficult for the donors Support from the family and health professionals was seen as very important in the assessment process They were afraid of the operation and tried not to think about organ rejection They stated that the information from the doctors was not very clear Financial cost: transport, accommodation, loss of income Interference in their daily life in order to do the tests

(Continues)

TABLE 3 (Continued)

Author(s), year, country	Objective	Study design	Sample	Key results
Maghen *et al.* (2018), USA	To describe the spirituality and religiosity of non-directed donors (NDDs) and its influence on their motivations to donate and the overall donation experiences	Qualitative, Grounded theory, In-depth interview	30 Altruistic kidney donors, (the results are on 16)	For NDDs, spirituality and religiosity served as a support mechanism: **a)** To motivate the donation: having received a religious education it contributed to their wish to donate. Donating was seen as a religious opportunity (to be chosen or obtain a spiritual prize) **b)** During the donation process: help cope with their fears and the risks of donating **c)** To improve their experiences after the donation: grateful for having been able to donate and help somebody
Manera *et al.* (2017), Australia and Canada	To describe the experiences and expectations of living kidney donors regarding follow-up and self-care after donation	Qualitative, Focus group	123 Living kidney donors	Four themes emerged: Lacking identification as a patient: The donors had trust in their good health Empowerment for health: They became aware of healthy habits and needed health education Safety net and reassurance: They were grateful for the psychosocial support network after the donation Neglect and inattention of care: The donors with post-operative complications felt poorly attended to; caring for the recipient at home was a great challenge; they received no help to cope with the economic costs of the donation
McGrath *et al.* (2012), Australia	To explore the experience with decision-making to be a live donor for renal transplant	Qualitative, Open interview	19 Living kidney donors	The decision to become kidney donors was positive, easy and fast They offered to be donors themselves Motivated to improve the quality of life of the recipient and to avoid complications, suffering and possible death They do not consider donating a heroic act
McGrath & Holewa (2012), Australia	To understand the financial impact of live kidney donation on the donor	Qualitative, Semi-structured interview	20 Potential living kidney donors	Financial difficulties were detected: **(1)** Economic cost of doing some of the tests, travelling costs **(2)** Regarding work: Loss of income during surgery and recovery or lack of sick leave The financial impact of donating a kidney is greater for those who live outside the metropolitan area
Meyer *et al.* (2017), Norway	To provide insight into donors' subjective meanings and interpretation of their experiences ~10 years after donation.	Qualitative, In-depth interview	16 Living kidney donors	There are fluctuating experiences during the donation: **(1)** The recipient outcome justified long-term experiences **(2)** Family dynamics - tension still under the surface **(3)** Ambivalence - health versus the need for regular follow-up **(4)** Life must go on
Pronk *et al.* (2018), Netherlands	To investigate why patients engaged in public solicitation (PS) and what they experienced during PS	Qualitative, Semi-structured interview	20 Recipients	Recipients ask for a kidney through PS for several reasons: To avoid endangering the health of somebody in their social-family network; ease of access to the network; and an urgent need to improve their health Experience during the PS: It gave them hope, they gained good support from people they knew and did not know, they experienced many emotions (disillusion, vulnerability, feeling obliged to return the gift), and they saw the donation process as slow and with little information

(Continues)

TABLE 3 (Continued)

Author(s), year, country	Objective	Study design	Sample	Key results
Shaw & Bell (2015), New Zealand	To document living kidney donors' views regarding recompense and payment for organ donation, based on their experience	Qualitative, Phenomenology, Semi-structured and In-depth interviews	25 Living kidney donors	The donation involved direct economic costs (travelling, accommodation, medication expenses) and indirect ones (loss of income and difficulty in paying for everyday expenses) The donors see the economic difficulties as obstacles to donating, and propose that the financial costs involved be reimbursed and paid for as a form of compensation The donors do not agree with the commercialisation of organs
Tong *et al.* (2012b), New Zealand	To elicit the motivations and experiences of non-directed living kidney donors	Qualitative, in-depth interview	18 Non-directed kidney donors	Six themes appear: **1)** Motivated to provide life opportunities for the recipient **2)** The decision was made individually and from a position of stability **3)** They minimise the risks to their own health in favour of the well-being of the recipient **4)** They respect the decision of the recipient with regard to anonymity and are grateful to establish communication and know the results on the health of the recipient **5)** They felt informed and psych-ologically prepared for the donation **6)** They obtain physical benefits, satisfaction, self-esteem and not regret
Ummel & Achille (2016), Canada	To examine the reciprocal influence between donors and recipients across the transplantation process	Qualitative, Phenomenology, In-depth interview	5 Donor–recipient dyads	Experience of the illness was more difficult for the recipients that did dialysis The donors offered the kidney and it was difficult for the recipients to accept it For the donors, pre-transplant screening created stress and investment of time Surgery was not unpleasant for the donors and the recipients focused on the positive feelings of having received an organ Donating is experienced as self-realisation and satisfaction at seeing the recipient's quality of life improve. The donated organ no longer belongs to them and they do not expect anything in return Donating within a genetic and emotional relationship is related to family obligations, and with altruism in casual relationships
Williams *et al.* (2009), Australia	To explore and describe the experiences of persons who had donated a kidney within Western Australia	Qualitative, Grounded theory, In-depth interview	18 Living kidney donors	The donors experienced 2 types of reaction after the donation: Physical reactions: post-operative physical discomfort, slower than expected recovery, no grief for the donated organ Psychological reactions: Positive (donating is positive, satisfaction at seeing the health of the recipient improve) and negative (feelings of sadness in the post-operative phase, concern for the health of the recipient and fear of organ rejection)

Table 3: Summary of the included studies.

2009), even those donors who in the long-term have developed chronic kidney disease (Halverson *et al.* 2018). The positive feelings are reinforced by the gratitude of the recipient and the recognition of family and friends (Farahani *et al.* 2016b).

Another personal benefit is seen in the feelings of union that donors experience with the recipient (Agerskov *et al.* 2016) and with the family (Farahani *et al.* 2016b). The assessment period can create a stronger bond between the donor and recipient (Agerskov *et al.* 2018), and there are studies on the post-operative phase that show that the relationship remains close and does not change (Andersen *et al.* 2007), while other studies highlight that it improves (Andersen *et al.* 2005).

Non-directed kidney donors also experience feelings of satisfaction and greater self-esteem after the donation (Tong *et al.* 2012b; Challenor & Watts 2014).

THEME D2: DIFFICULTIES AND STRESSORS OF THE DONOR

D2.1. PERSONAL INVESTMENT

In the reviewed studies, we found that the donation process involved a personal investment. Interruption of the donor's daily life to go through the tests (Hanson *et al.* 2017) and to recover requires time and personal effort (Adams-Leander 2011). Occasionally, it is seen as a long and fairly inflexible process that fails to adapt to the active life of the donors (Cuesta-Briand *et al.* 2015)

D2.2. ECONOMIC IMPACT

The donation process entails direct and indirect economic difficulties. The costs of travelling, parking and accommodation when going through the tests are difficulties that most donors mention (Hanson *et al.* 2017; Manera *et al.* 2017), especially those that live in non-metropolitan areas (McGrath & Holewa 2012). There are also costs related to work, such as lost wages and loss of income during the assessment phase and post-operative recovery that makes it difficult to cover the personal and family expenses (Cuesta-Briand *et al.* 2015). Some donors say that economic difficulties can act as an impediment to donating (Shaw & Bell 2015).

D2.3. PHYSICAL IMPACT

The post-operative phase in donors entails physical discomfort like pain and nausea (Andersen *et al.* 2005; Gill & Lowes 2008) that in some cases are expected (Bertelsen *et al.* 2015) and in others are not (Agerskov *et al.* 2016). There is evidence that before the transplant some donors show unrealistic expectations about their physical recovery (Williams *et al.* 2009; Cuesta-Briand *et al.* 2015). Physical effects like feeling tired and lacking energy are common up to several months after the operation or up to a year (Gill & Lowes 2008).

D2.4. MENTAL IMPACT

During the whole donation process a number of concerns and fears appear. During the waiting period of the assessment process there is concern to be chosen and about failing as a donor (Hanson *et al.* 2017). In fact, when the possible donor is rejected, feelings of disappointment and frustration arise (Agerskov *et al.* 2018). Fear of surgery is common in donors; some of them have never been through it (Andersen *et al.* 2005; Hanson *et al.* 2017). After the donation, there appear concerns about the recovery of the recipient and not so much about the health of the donor (Andersen *et al.* 2005), although in some studies donors show concern about their own health (Agerskov *et al.* 2016, 2018). Another frequent fear of donors is rejection of the transplanted organ (Williams *et al.* 2009; Bertelsen *et al.* 2015).

The mild depression that we find in the studies is related to exhaustion and lack of energy after the surgery and also the difficulty they have during the first few weeks of carrying out the normal tasks they did before the donation (Andersen *et al.* 2007; Adams-Leander 2011). One of the stressors for the donors after hospitalisation is the concern about family and work responsibilities. On many occasions, family functions like taking care of the children or being the carer of the recipient can impede the donor's recovery (Manera *et al.* 2017).

D2.5. OVERCOMING OPPOSITION

Sometimes it is difficult at first for donors to persuade the recipient to accept their kidney. When the donation occurs within the family, the donor sometimes meets resistance from the recipient until she/he accepts it (Davis *et al.* 2017).

Furthermore, there is also resistance from the community (Hanson *et al.* 2017). Non-directed donors often come up against opposition from family and friends, and this creates worry and fear of disapproval (Clarke *et al.* 2014), which can affect family relationships (Challenor & Watts 2014). Family tensions can also arise between members of the same family when it comes to deciding who the donor will be (Meyer *et al.* 2017).

THEME D3: DEFICIENCIES IN THE HEALTH SYSTEM

D3.1. LACK OF INFORMATION

During the donation process, a lack of information in different periods was mentioned. During the assessment, some donors reported incomplete information and lack of clarity by the health professionals (Adams-Leander 2011; Hanson *et al.* 2017). Lack of communication produces frustration and impotence (Agerskov *et al.* 2018). Information from health professionals when unexpected post-surgical problems arise is considered crucial in order to transmit confidence and calm to the donor (Agerskov *et al.* 2016).

D3.2. LACK OF ATTENTIVENESS

In some studies, it was found that post-donation medical follow-up was poorly protocolised and donor expectations were not met (Andersen *et al.* 2007; Gill 2012). In complicated post-operative cases, feelings of being poorly attended to and abandonment by the health system arose (Bertelsen *et al.* 2015; Manera *et al.* 2017). Other studies found that the medical follow-up was focused more on the renal parameters than on the overall well-being of the donor (Manera *et al.* 2017; Meyer *et al.* 2017).

RESULTS OF THE STUDIES IN RECIPIENTS

Two themes emerged when analysing the studies on kidney recipients. Receiving a kidney is a positive experience but there are certain difficulties and stressors.

THEME RI: RECEIVING AS A POSITIVE EXPERIENCE

R1.1. POSITIVE FEELINGS

Kidney recipients are optimistic and motivated to have a better life after the transplant. Positive feelings are very common among recipients during the whole transplant process, even at the most delicate post-operative moment (Ummel & Achille 2016). Receiving a kidney is a great gift (Bertelsen *et al.* 2015). The feeling of gratitude towards the donor is present in all recipients, although there is only a sense of obligation to return the gift in recipients who engaged in the public solicitation (Pronk *et al.* 2018).

R1.2. SIGNIFICANT EXPERIENCE

Receiving a renal transplant is a significant experience that not only improves life expectancy but also gives recipients freedom and enables them to travel, to go back to work and to make plans for the future again (Ghahramani *et al.* 2014; Gill & Lowes 2008; Ummel & Achille 2016). The emotional support the recipients receive from their family, and above all from the donor, is very important for them (Gill 2012; Davis *et al.* 2017). The perceived relationship with the donor after the transplant is the same or even better than before going through the transplant process (Gill & Lowes 2008).

THEME R2: DIFFICULTIES AND STRESSORS OF THE RECIPIENT

R2.1. A DIFFICULT DECISION TO MAKE

The recipients do not ask for the kidney; it is a member of their family that offers it to them. At first, they do not accept this offer, and a period of reflection is required before they can do so (Gill & Lowes 2008; Gill 2012; Ummel & Achille 2016; Davis *et al.* 2017). Some patients with chronic kidney disease said that they would prefer an anonymous donor due to concern about feeling a sense of life-long indebtedness (Ghahramani *et al.* 2014), and others publicly solicit a kidney on social media (Pronk *et al.* 2018) in order not to put a family member at risk. The donors that developed kidney disease refuse to receive a kidney from their relatives to avoid exposing them to the risks that they faced (Halverson *et al.* 2018).

R2.2. FEARS AND CONCERNS

Concern for the health of the donor is expressed by all recipients, and can become a significant stressor in the transplantation process (Gill 2012; Ghahramani *et al*. 2014). There is a concern that the tedious pre-transplant testing and workup expenses act as an obstacle for the transplant (Ghahramani *et al.* 2014). Recipients express fear about the surgery and post-operative pain, but fear of the donated organ being rejected is greater (Gill 2012).

DISCUSSION

This review provided information on the similarities and differences between the renal transplant experiences of donors and recipients. Although both the donors and recipients apparently experienced the transplant as something positive, they did so for different reasons: for the donors, seeing the life of the recipients improve and for their own personal benefits (Kisch *et al.* 2018); as for the recipient, experiencing positive feelings (improving their life, gratitude towards the donor and so forth) and the fact that the transplant enabled them to enjoy more freedom (to travel, make plans and work).

With regards to returning to work, the literature shows less optimistic results (Tzvetanov *et al.* 2014; De Pascuale *et al.* 2018).

Both the donors and recipients in the qualitative studies selected in this review noted that support from the family, health professionals and even the community were important when coping with the renal transplant process. We can affirm that when the donation takes place within the family there are greater feelings of union between donor and recipient. In concordance with Ummel *et al.* (2011), after the transplant, in most cases, the relationship between the two remains the same or even improves.

Although, as Tong points out (2012), the donors were praised by the recipient and the family, we can state that the donors did not consider their action a heroic one. It can be said that living-donor kidney transplantation is a significant action for both the donor and the recipient. Another theme that our systematic review provided is that the transplant entails certain difficulties and stressors for both the donors and recipients of the transplant, with each experiencing it differently.

The decision to donate is a voluntary one, albeit donating within the extended family is related to fulfilling the expectations of the roles and obligations of relatives (Ummel & Achille 2016). It is generally experienced naturally, although it occasionally leads to family tensions and can affect future relations (Meyer *et al.* 2017; Ralph *et al.* 2017). We, therefore, consider it important that health professionals take into account the family dynamics from the beginning of the transplantation process. Altruistic donors also experienced family conflict. Just as reported in the meta-ethnography of Kisch *et al.* (2018), they experienced negative family situations as a result of their decision to become donors.

A fast and firm decision to donate counteracted the difficulty that the recipient had in accepting a kidney from a family member, since there was concern about the health of, and risks for, the donor. This finding was not so consistent in other reviews of studies carried out on recipients. We consider it necessary for health professionals to take into account this difficulty so that they can provide support for the recipient in the period before the transplant.

In this review, with the exception of Pronk's (2018) public solicitation, we saw that it is not the recipient who asks for the kidney but rather the donor that offers it. Hanson *et al.* (2015) even stated that one of the difficulties of the recipient is fear of refusal when soliciting a kidney.

Donation involves a personal investment and both direct and indirect economic costs. One study of 912 living donors (Przech *et al.* 2018) showed that the economic loss involved could act as an obstacle to living donations. Ruck *et al.* (2018) recommends identifying those donors with a greater sense of financial burden and providing them with support. Jacobs' (2015) study proved that although the donation is usually satisfactory, there are also negative results such as financial burden, loss of salary and emotional problems.

In this review, we found mild depression among the donors related to exhaustion and lack of energy in the immediate post-operative phase. According to one study (Holscher *et al.* 2018), the prevalence of anxiety and depression after the donation is low, although a post-donation psychosocial follow-up is recommended.

We have seen in this review that donors described the physical effects of the donation and that they occasionally showed unrealistic expectations, minimise the risks and were more concerned about the health of the recipient than their own. Several studies demonstrate the health risks that donation entails for the donors (Reese *et al.* 2015; Menjivar *et al.* 2018). We thus recommend to fully discuss this with potential donors from the beginning of the transplantation process.

Kidney recipients were concerned about the health of the donors, and some preferred to have an anonymous donor or to engage in public solicitation. Hanson *et al.* (2015) and Waterman *et al.* (2006) showed that some preferred a deceased donor due to fear of complications for the donor. Davis *et al.* (2017) pointed to another difficulty in recipients; denying or minimising the severity of the disease delays the possibility of a living-donor transplant. Accepting the needs for attention and flexibility helps to accept the illness and to cope with the transplantation process (Hamama-Raz *et al.* 2018; Valizadeh Zare *et al.* 2018).

Finally, our review found that kidney donors, unlike recipients, experienced deficiency in the health system. While many donors felt well-informed by health professionals, some found deficiencies in the information process and the attention provided. Kisch *et al.* (2018) pointed to the donor's feeling of being alone and abandoned after the donation; and Sanner *et al.* (2011) stated that 25% of living-donor kidney recipients think that the donors were abandoned by the health system after the nephrectomy. In the review of Ummel *et al.* (2011), continuous follow-up after the donation by the health care team was suggested;

and the new guidelines regarding care of kidney donors recommend an annual health and psychosocial assessment (Lentine *et al.* 2017).

The qualitative research of the reviewed studies has enabled a deeper understanding of the experiences of donors and recipients both before and after the renal transplant. However, this review identified areas that had received little attention, such as the experiences of donors turned down in the assessment period and the perception of donors and recipients when there is a rejection of the graft. The understanding of these themes can help the health services to act in difficult phases of the transplantation.

We can see that most studies continue exploring the donation experiences of living kidney donors. However, we see the need to examine the perspectives and experiences of recipients during the whole renal transplantation process, and especially to study donor–recipient dyads.

The studies included in this review cover emotional, non-emotional, casual and non-directed relations between donors and recipients. We identified a lack of donors and recipients voices that had undergone a kidney transplant through kidney exchange programmes (Kute *et al.* 2018).

LIMITATIONS

First, most of the articles are focused on studying the experiences of donors and recipients in a specific phase of the transplantation process, so it is difficult to follow and understand their experience of the whole transplantation process. Second, the few studies that we have obtained on recipients limits the transferability of the findings to other kidney recipients. And finally, we reviewed studies in English, French and Spanish, meaning that studies in other languages or context were not identified. We recommend caution while extrapolating the conclusions of this review.

PRACTICAL IMPLICATIONS

The review helps us to understand the motives, experience and significance of the transplantation for the donors and recipients. This knowledge will help us to perfect and standardise procedures for care, treatment and support of kidney donors and recipients. This review is also of value because it is important to inform donors and recipients of the risks and difficulties that might arise, but also of the possible benefits for both.

CONCLUSION

This systematic review shows how donating and receiving a kidney is a positive experience that also involves certain difficulties and stressors for both the donors and recipients. When we analyse this experience and these difficulties in depth, we see that they are not the same for each one of them. Further, it is only the donors that perceive a deficiency in the health system.

CONFLICT OF INTERESTS

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

LR: Lead author; LR, EO and MH: Developed the systematic review protocol; MS and SB: Reviewed, modified and approved the manuscript; EM: Contributed and approved the manuscript.

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