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Living kidney donor and recipient perspectives on their relationship: longitudinal semi-structured interviews

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Living kidney donor and recipient perspectives on their relationship: longitudinal semi-structured interviews

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Running Title: Living kidney donor-recipient relationship: longitudinal interview study

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Abbreviations:

U.K. United Kingdom

U.S. United States

Abstract

Background and objectives: Many donors and recipients report an improved bond post transplantation; however unexpected conflicts and tension may also occur. Insights into the lived experiences of the donor-recipient relationship can inform strategies for interventions and support. We aimed to describe donor and recipient expectations and experiences of their relationship before and after living kidney donor transplantation.

Design, setting and participants: Semi-structured interviews were conducted with 16 donor-recipient pairs before the transplant and 11-14 months post-transplant. Transcripts were analysed thematically.

Results: We identified seven themes (with respective subthemes): donation as enacting familial responsibility for care; analytical decision making to mitigate regret (avoiding anticipated regret and maintaining control, removing emotional impulsivity); strengthened interpersonal ties (gaining a deeper appreciation among family members, stronger empathy for each other, improving social participation); instability of relational impacts (anger and aggression threatening dynamics, unanticipated stress and emotional lability, triggering familial tension); renegotiating social roles (unexpected continuation of caregiving responsibilities, inability to relinquish the caregiving role, disappointment with unfulfilled renewal of intimacy, dissatisfaction over discrepant energy levels); guilt over unmet expectations; and inevitability of the gift relationship (vague and transient indebtedness, expectation of reciprocity, transferring kidney ownership).

Conclusions: Donor-recipient relationships may be improved through increased empathy, appreciation, and ability to participate in life together, however unfulfilled expectations and behavioural and emotional changes, particularly in recipients attributed to immunosuppression, remain unresolved consequences of living kidney donor transplantation. Education and counselling to help donors and recipients adjust to potential changes in relationship dynamics may help protect and foster relational stability post-donation.

Article Summary

Strengths and limitations of this study

- We conducted longitudinal interviews with the same donor-recipient dyads prior to donation/transplantation then one year later and this provided access to changes in perspectives and experiences of the donor-recipient relationship in “real-time”
- All participants were English-speaking and the majority had attained a tertiary level of education.

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Introduction

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4 Living kidney donor transplantation confers superior survival and quality of life benefits for most patients
5 with end-stage kidney disease compared with dialysis.¹ Rates of living kidney donor transplantation have
6 risen worldwide, comprising approximately 30% to 50% of all kidney transplants in high income countries,
7 with the majority of donors being parents, spouses or siblings.²⁻⁵ While quality of life can improve for many
8 recipients,⁶⁻⁸ donors and recipients have to renegotiate their social roles, identity and relationships.^{8,9}

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17 Living kidney donation can strengthen the donor-recipient relationship, character
18 ised by greater perceived emotional support and a unique emotional connection.^{8,10} However, some donor-
19 recipient dyads have reported donation-related conflict and tension, marked by feelings of rivalry,
20 abandonment, guilt, disappointment, anger and jealousy.¹⁰⁻¹³ Poor family dynamics are associated with post-
21 donation depression and decreased social functioning in recipients of a living kidney donor transplant, to a
22 greater extent than in recipients of deceased donation.¹⁴ In a recent study,¹⁵ living kidney donors prioritised
23 the donor-recipient relationship as the fifth most important outcome of donation, even above overall life
24 satisfaction, mortality, pain and kidney failure. Yet, there is limited data on the donor-recipient relationship.

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36 Clinicians regard evaluating the donor-recipient relationship as ethically necessary to minimise the risk of
37 undue coercion.¹⁶ The donor-recipient relationship after donation is variable across dyads,^{8,12,17} however
38 little is known regarding the mechanisms underlying such differences, nor how dyads perceive pathways to
39 relationship outcomes. Most studies have focused on living kidney donor perspectives post-donation,^{8,17-19}
40 insight into the lived experience of the donor-recipient relationship from their perspective before and after
41 donation is limited. We aimed to collect longitudinal data on donor and recipient expectations and
42 perspectives of their relationship in living kidney donor transplantation, which may inform strategies to
43 mitigate risks of relationship tension and conflict and support relationship resilience, thereby contributing to
44 improved outcomes in living kidney donor transplantation.

Materials and methods

Participant selection

Living kidney donors and their recipients were recruited from three transplant units in Sydney, Australia. They were purposively selected to ensure a range of demographic (including age, gender, donor relationship) and clinical (including dialysis modality, comorbidities) characteristics. Participant pairs were eligible if they comprised a spousal, sibling, or parent living kidney donor (as approximately 70 percent of live donations in the U.S., Canada, Australia and New Zealand are from spouses or biologically related donors^{2 4 20}) and a recipient with a confirmed transplant date. All participants had to be English speaking, over 18 years of age, and able to give written informed consent. Western Sydney Local Health District (LHD), Sydney LHD and South-Eastern Sydney LHD approved the study.

Data collection

The interview guide was developed based on a systematic review of donor-recipient perspectives¹⁰ and investigator input (Supplementary File 1). One author (A.F.R) conducted two longitudinal, individual semi-structured interviews with each participant, during the month prior to their donation/transplant, and 11-14 months post-donation/transplant. The interviews were conducted face-to-face in their home, office or dialysis unit, or via telephone if this was not possible. A.F.R was not previously known to participants, not involved in their clinical care. For feasibility, our target sample was 30 participants. Interviews averaged thirty minutes in duration and were audio-taped and transcribed.

Analysis

Using the principles of grounded theory²¹ and thematic analysis,²² A.F.R read through the transcripts and inductively identified preliminary concepts. The transcripts were entered into data management software

1 HyperRESEARCH (ResearchWare Inc, United States, Version 3.7.3) where A.F.R reviewed the transcripts
2 line-by-line (by dyads) and coded emerging concepts. A.F.R and A.T met frequently to refine the coding
3 structure. The emergent findings across all dyads were compared. Similar concepts were grouped into
4 themes, and patterns between themes and subthemes were identified and mapped into a thematic schema.
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6 The themes were reviewed by authors (T.G, C.S.H, and A.J) who read the transcripts and discussed these
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8 with A.F.R. This form of investigator triangulation can enhance the analytical framework and ensures that
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10 the findings reflect the full range and depth of the data.
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16 *Patient and public involvement*

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21 The donor-recipient relationship has been identified as a research priority by patients,²³ however patients
22 were not involved in the design of this study. On publication of this manuscript, a summary of the study
23 results was disseminated back to participants.
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30 **Results**

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34 Of the 28 donor-recipient pairs approached, 16 pairs participated. Reasons for non-participation included
35 lack of time and avoiding the risk of jeopardising the stability of their relationship prior to the transplant.
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37 From October 2014 to June 2017, we conducted 32 pre-transplant interviews (16 donors, 16 recipients) and
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39 29 post-transplant interviews (14 donors, 15 recipients). One pair was excluded from the post-donation
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41 interviews as the recipient received a deceased donor kidney, and one donor could not be contacted for the
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43 second interview. The characteristics of participants are shown in Tables 1 and 2. Nine (56%) donors and 11
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45 (69%) recipients were male. Eight (50%) were spousal dyads in which four donors were female, five (31%)
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47 were sibling pairs, and three (19%) were parent-child dyads. On average, each interview was 30 minutes in
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49 duration, and 53 (87%) interviews were conducted in-person.
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1 We identified seven themes: donation as enacting familial responsibility for care, analytical decision making
2 to mitigate regret, strengthened interpersonal ties, instability of relational impact, renegotiating social roles,
3 guilt over unmet expectations; and inevitability of the gift relationship. The subthemes are described below,
4 and quotations to illustrate each theme are provided in Table 3. Figure 1 depicts a conceptual schema of the
5 relationships among themes.
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17 Some donors viewed donation as a ‘continuation of the nurturing process’ for their family member, and this
18 was intensified in mothers and wives. Some felt somewhat at fault for their recipient’s illness and felt
19 compelled to donate. One mother felt “a little bit responsible [for her son’s kidney disease] that we didn’t
20 have him checked out.” Another donor reported that their clinician went “absolutely ballistic” at her for not
21 knowing that her spouse had kidney failure (prior to diagnosis). Some donors believed they would endure
22 unbearable guilt if they did not take care of their family by donating a kidney.
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32 **Analytical decision making to mitigate regret** 33 34 35

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37 *Avoiding anticipated regret and maintaining control:* Some participants took into account tension,
38 decisional regret and feelings of guilt when making decisions about donating or accepting a kidney.
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40 Recipients refused to accept donations from family members who they anticipated would use it against them
41 in the future to ‘control situations’ such as to win arguments, to make them change behaviours (e.g. drinking
42 alcohol) or in a potential divorce settlement. Some donors did not want to regret donating and therefore did
43 not want to donate to recipients who they perceived had either “contributed to [their] own kidney problems”
44 (e.g. through excessive drinking) or had disappointed or hurt them as they did not “trust them to look after
45 such a gift”.
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1 *Removing emotional impulsivity:* To preserve the stability of their relationship, some participants
2 approached their decision pragmatically. Some donor-recipient pairs communicated about all possible
3 relationship consequences, including divorce, to ensure they were able to accept these risks. One donor
4 completed his work-up without the knowledge of the recipient and then communicated his offer of donation
5 via e-mail to allow the recipient “a chance to absorb it” so they would not feel obligated to respond
6 immediately. The donor outlined a logical case for why he should be the donor and emphasised that the offer
7 was “without strings” to minimise potential disruption to their relationship.
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16 **Strengthened interpersonal ties**

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21 *Gaining a deeper appreciation among family members:* While some participants believed their relationship
22 did not change post-transplant, others felt they developed an intangible “special bond” and became closer
23 through increased contact. Spousal dyads felt they had “seen the worst and best bits” of each other through
24 the “difficult process” of donation and become stronger and more honest with each other. Some viewed the
25 commitment of donation akin to marriage and became more aware of how their spouse “treasured them”.
26 Some donors felt that their recipient’s family members displayed a “warmer attitude” and gratitude towards
27 them.
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39 *Stronger empathy for each other:* Some donors and recipients became more focused on each other’s
40 wellbeing than their own. For some donors, the clinical workup was their first experience of undergoing
41 medical tests and waiting in hospitals and they gained a newfound appreciation of the discomfort,
42 uncertainty and inconvenience their recipient had experienced in hospital. Recipients viewed their donor as
43 ‘brave’ but held concerns about their donor’s health.
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52 *Improving social participation:* Spousal pairs anticipated that recipients would have increased energy to
53 participate in activities after transplant, giving them “a better life together”. They looked forward to being
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able to do activities together including travelling, walking, bike riding, going to the beach and dancing. For some pairs, these expectations were realised and they felt “happier” and “stronger” as a couple.

Instability of relational impacts

Anger and aggression threatening dynamics: Both donors and recipients worried about the potential impact of steroid medication (in particular, prednisone) on the recipient’s ‘personality’ and how this could affect their relationship. Recipients were concerned that they “would not be the same person” on medication, and they may become angry, depressed, “grumpy and moody” towards their partner. One spousal donor was worried that she may leave her recipient if “he ends up too difficult to live with”. After the transplant, donors felt stressed in having to cope with the anger and irritability experienced by their recipient – “like waiting for a ticking time bomb to go off”.

Unanticipated stress and emotional lability: The upcoming transplant was a priority and consumed the time and energy of some spousal pairs who experienced increased tension and arguments, which they attributed to the stress of the donation process (e.g. uncertainty regarding donor eligibility and waiting for transplant confirmation) and upcoming surgery. After donation, some recipients experienced exaggerated changes in mood and/or a reoccurrence of previous mental health disorders (including depression and bipolar disorders) which they believed were due to the stress, adjustment and steroids, and which affected their relationship.

Triggering familial tension: For some, in particular parent-to-child dyads, the donation became a source of stress in their relationships with other family members. Recipients experienced “snide comments” from and arguments with other family members (e.g. sibling, other parent or parent-in-law) who did not agree or were concerned for the donor. Such recipients felt this compounded their feelings of guilt and worry about the transplant. Donors and recipients also noted friction in their relationships with other family members who did not offer to donate. Some donors believed the donation triggered arguments within the extended family

1 who challenged the donor's motives and instigated family discussion of the Will of the recipient, especially
2 in blended families.
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6 **Renegotiating social roles**

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10 *Unexpected continuation of caregiving responsibilities:* Spousal donors expected their role as a 'caregiver'
11 to diminish post-transplant. For some donors whose recipient had complications and side effects (e.g. BK
12 virus, diabetes), they were disappointed in having to still bear caregiving responsibilities. They described
13 recovery as a "rollercoaster" which required them to exercise tolerance and patience towards their recipient.
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21 *Inability to relinquish the caregiving role:* Some spousal recipients felt their donors wanted to continue
22 caring for them post-transplant and were worried about hurting their donor's feelings by informing them that
23 they no longer required their assistance such as being driven to attend follow up clinic. One spousal donor
24 was offended when their recipient began to do activities alone (e.g. shopping, exercise), which they had
25 normally done together.
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34 *Disappointment with unfulfilled renewal of intimacy:* Some spousal pairs eagerly anticipated improved
35 physical affection and intimacy post-transplant, with one donor citing this as the primary reason for her
36 donation. Recipients reported that clinicians advised them that increased libido was a side effect of steroid
37 medication. However, some recipients were afraid to have intercourse whilst on immunosuppressants as this
38 could result in urinary tract infections. For other recipients, intercourse was painful, or they did not
39 experience increased libido. Some recipients did experience an increased libido but became frustrated when
40 this was not matched by a similar change in their spousal donor. Recipients were reluctant to discuss their
41 sexual concerns with their clinicians as they believed this would be regarded as peripheral to the primary
42 focus on their health.
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Dissatisfaction over discrepant energy levels: In some spousal pairs, the recipient's vitality increased and surpassed that of their donor, shifting the relationship dynamic and causing relationship tension as the recipient wanted to lead a more fast-paced and active lifestyle than their partner. Conversely, when recipients did not experience their expected 'boost' in vigour, donors felt disappointed and frustrated that they were unable to engage in their desired shared lifestyle.

13 **Guilt over unmet expectations**

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Before the transplant, recipients worried that if their desired physical, psychological and social improvements were not achieved after the operation, they may feel regret and be blamed by others for accepting the kidney donation. Some recipients, despite having a successful transplant, did not feel "stronger and better", often due to comorbidities e.g. diabetes. Such recipients felt they had failed their donors, were "wasting" their donor's kidney and efforts, and worried they would be blamed by their donor or other family members.

32 **Inevitability of the gift relationship**

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Vague and transient indebtedness: Recipients were "eternally grateful" to their donor and felt indebted to them, however this was "a subconscious thing" and "not a real issue" and diminished over time. They believed the best way to show their appreciation was to look after their health and verbally thank the donor.

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Expectation of reciprocity: Some spousal donors felt disgruntled that their recipient was not more openly appreciative of them. This mainly occurred when the donor was frustrated with their recipient, for example, for not supporting them in a family argument, not paying for something, or if they believed they were not making an effort in their relationship. However, donors felt uneasy and guilty about having such thoughts.

1 *Transferring kidney ownership:* Donors were conscious that the imbalance of the one-way gift had the
2 potential to cause unease in their relationship and did not want their recipient to feel guilty. They
3 conceptualised the kidney as a gift and were careful about how they discussed the kidney in front of the
4 recipient and encouraged their recipient to participate in physical activities and not to be overly cautious.
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6 Donors and recipients recalled being told by clinicians “once it’s out of you it’s not yours anymore”. Whilst
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8 some donors were initially anxious about the recipient’s health and wanted to “wrap them in cotton wool”,
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10 this lessened over time; they emphasised they had donated so their recipient could live life to the full.
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20 **Discussion**

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23 For donors and recipients, improved and strengthened relationships after living kidney donor transplantation
24 were marked by increased closeness and appreciation of each other, stronger empathy, more frequent
25 contact, and enhanced quality of life as a pair. At the same time, some dyads were confronted with conflict
26 and tension triggered or exacerbated by behavioural and emotional changes (anger, aggression, alterations in
27 mood in recipients related to steroid use), and disappointment with unfulfilled expectations of recovery of
28 health, re-establishing roles, and renewal of intimacy. Some donors and recipients were aware of potential
29 relational strains such as anticipated guilt and indebtedness of the recipient and changes in relationship
30 dynamics because of the one-sided ‘gift relationship’ and donors emphasised that recipients should not feel
31 any obligation or be overly cautious.
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45 There were differences in the expectations and experiences of spousal dyads when compared with parent-
46 child and sibling pairs. Spousal pairs expected that the donation/transplant would enhance overall quality of
47 life as a couple, which is in accordance with previous research.^{9 11 24} For some donors, this was a key
48 motivation for donating a kidney, which may explain why spousal couples were focussed on psychosocial
49 impacts of living kidney donor transplantation.¹⁵ Any unmet expectations of retaining a caregiver role (for
50 donors), improved social life, and increased intimacy caused disappointment and frustration in the donor-
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1 recipient relationship. Spousal pairs also reported increased tension and arguments prior to the transplant.
2 The donor in the spousal dyad has multiple and simultaneous roles in the relationship – caregiver, spouse
3 and kidney donor; and we speculate that this comprised an additional stressor on the donor-recipient
4 relationship. Further, spousal donor candidates have reported feeling more responsible for the recipient's
5 health post-donation, again likely due to their multiple roles.²⁵ With the spousal donor and recipient
6 undergoing workup for transplant together, this process became a priority in their life and led to increased
7 tension and disruption. Previous research has found that spousal donors (when compared with genetically
8 related donors) expect longer recovery times, more psychological problems and more pain and discomfort
9 associated with surgery and recovery,²⁵ possibly compounding the experienced pre-donation stress.
10 However, some spousal dyads felt that going through the donation process bolstered resilience in their
11 relationship.
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26 Sibling pairs, when compared with spousal and parent-child dyads, seemed to be more analytical in their
27 approach to decision making regarding donation with an acute awareness of the imbalance in the power
28 dynamics due to the one-way gift. All sibling recipients in our study were either married and/or resided in
29 another state to their donor, thus, unlike spousal and parent donors, the donor was less present in the
30 recipient's day-to-day life and did not hold a caregiving role. This may explain why sibling donors give
31 more consideration to the risks of donation and their long term health outcomes than spouses or parent
32 donors.²⁶
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43 Donor-recipient pairs felt unprepared and unable to manage side-effects of immunosuppression, in
44 particular, irritability and aggression. While the adverse effects of immunosuppressants (particularly
45 steroids) on behaviour and mood have been well-established,^{27 28} little attention has been paid to behavioural
46 strategies to assist patients and their families with such effects. In severe cases, recipients may be prescribed
47 mood altering and stabilising medications (e.g. antidepressants, antipsychotics and anti-anxiety
48 medication)²⁹ however evidence for this is limited to case studies and pilot studies.³⁰⁻³² Donors and
49 recipients were also reluctant to discuss problems with their mood and sexual difficulties with their clinical
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1 team as they believed they did not have enough time to talk about issues secondary to the kidney. However,
2 sexual problems have been reported in over 60% of renal transplant recipients^{33 34} and have been strongly
3 correlated with decreased quality of life up to five years post-transplant.³³
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8 Studies have shown that unrealised expectations of donors and/or recipients of life post transplantation,
9 contributed to difficulties in their relationship.¹⁰ For example, donors and/or recipients were disappointed
10 that transplantation had not led to the desired level of improvement in physical and emotional participation
11 in family life. Whilst our study confirms these previous findings we also found that in some spousal couples,
12 functioning (e.g. energy levels, libido and level of independence) improved in recipients, and surpassed that
13 of their donor, which led to tension in the donor-recipient relationship. In spousal dyads, it is common that
14 the illness has become completely embedded in their relationship and identities, with an enforced imbalance
15 of power and lack of independence in relational roles due to the illness.³⁵ Successful transplantation
16 represents a milestone where both patient and spouse must communicate effectively and re-establish healthy
17 boundaries and identities.
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32 We conducted longitudinal interviews with the same dyads prior to donation/transplantation then one year
33 later and this provided access to changes in perspectives and experiences in “real-time,” potentially allowing
34 more accurate recall of events and reflections.³⁶ This also enabled stronger rapport and thus participants may
35 have been more willing to disclose their perspectives more openly. We used purposive sampling to capture a
36 relatively diverse cross-section of donor-recipient dyads.
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45 However, there are potential study limitations. Some donors/recipients refused to participate to avoid the
46 risk of disturbing the stability of their relationship prior to the transplant, thus transferability of these
47 findings to those with such insecurities about their relationship remains unclear. All participants were
48 English-speaking and the majority had attained a tertiary level of education.
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1 Our study draws attention to the need for interventions and support for donors and recipients to manage
2 mood changes of recipients; tensions arising from the gift relationship; and adjustment of the identity and
3 roles post-transplant. We recommend incorporating education on strategies to cope with emotional lability
4 for both recipients and family members prior to transplantation. Additionally, this should be included in the
5 post-donation psychosocial review for both recipients and donors with referral to a psychiatrist if
6 indicated.³⁷ Psychological services can assist both recipients and donors with coping with recipient's
7 emotional lability through acceptance strategies, normalisation, behavioural strategies, improved
8 communication and problem-solving abilities.³⁸ Education regarding the nature of the one-way gift
9 relationship may help donors and recipients have a functional conceptualisation of the gift and ensure
10 recipients are not overwhelmed by feelings of guilt.³⁹ Facilitating access to relationship counselling may
11 assist spousal couples struggling with unmet expectations and adjustment in relational roles and identity
12 post-transplantation.³⁵

13 While living kidney donor guidelines⁴⁰⁻⁴⁶ recommend assessment of the donor-recipient relationship and
14 post-transplant expectations, guidelines for transplant recipients do not explicitly address this. Guidelines
15 recommend psychosocial follow-up of both donors and recipients, however the donor-recipient relationship
16 is not specifically addressed. Whilst some transplant centres administer quality of life measures (e.g. Short
17 Form 36) to review the psychosocial health and wellbeing in post-donation follow-up care,^{47 48} many of
18 these measures do not contain questions pertaining to sexual functioning and/or satisfaction and recipient
19 mood changes, which were highly important to donors and recipients, who were hesitant to discuss these
20 with clinicians. This calls for a need to include these domains in patient/donor-reported outcome measures.

21 In summary, living kidney donation can strengthen donor-recipient relationships, but for some pairs, may
22 also trigger unexpected conflict and tension and disappointment with unfulfilled expectations. Interventions
23 to address potential relationship difficulties are needed. In terms of post-transplant follow up, assessment of
24 the donor-recipient relationship requires discussion about adjustment in relational roles and relationship
25 dynamics, changes in emotional lability and sexual functioning, and donors/recipients should have access to

psychological services when required. A more comprehensive focus on protecting and supporting donor-recipient relationships may contribute to overall improved psychosocial outcomes and satisfaction in living kidney donor transplantation.

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Table 1. Demographic characteristics of the participants (Total N=32)

Characteristics	Donors n (%)	Recipients n (%)	Total n (%)
Gender			
Male	9 (56)	11 (69)	20 (64)
Female	7 (44)	5 (32)	12 (38)
Country of origin			
Australia	12 (75)	14 (88)	26 (81)
Other ^a	4 (25)	2 (13)	6 (19)
Age (years)			
20-39	1 (6)	1 (6)	3 (9)
40-49	4 (25)	6 (38)	9 (28)
50-59	5 (32)	3 (19)	8 (25)
60-69	3 (19)	5 (32)	8 (25)
70-79	3 (19)	1 (6)	4 (13)
Ethnicity			
Anglo Celtic	13 (81)	13 (81)	26 (81)
Other European	2 (13)	2 (13)	4 (13)
Aboriginal	1 (6)	1 (6)	2 (6)
Highest level of education			
Secondary	4 (25)	6 (38)	10 (31)
Tertiary – certificate/diploma	3 (19)	3 (19)	6 (19)
Tertiary – undergraduate degree	6 (38)	4 (25)	10 (31)
Tertiary – postgraduate degree	3 (19)	3 (19)	6 (19)
Religion			
Christianity	8 (50)	12 (75)	20 (63)
No religion	7 (44)	3 (19)	10 (31)
Buddhism	0 (0)	1 (6)	1 (3)
Other	1 (6)	0 (0)	1 (3)
Employment status^b			
Full time	5 (32)	9 (57)	14 (44)
Part time/casual	4 (25)	1 (6)	5 (16)
Retired/Pensioner	6 (38)	4 (25)	10 (31)
Not employed	0 (0)	2 (13)	2 (6)
Marital status			
Married/De-facto relationship	13 (81)	12 (75)	25 (78)
Divorced/separated	2 (13)	2 (13)	4 (13)
Single	1 (6)	2 (13)	3 (9)

^aOther includes: Greece, New Zealand, The Netherlands, Zambia, Zimbabwe; ^bN =31 as one participant did not provide data

Table 2. Clinical characteristics of the recipients (n=16)

Characteristics	n (%)
Relationship to donor	
Wife/female spouse	4 (25)
Husband/male spouse	4 (25)
Son/son-in-law	3 (19)
Brother	3 (19)
Sister	2 (13)
Time since diagnosis of kidney disease (years) ^a	
1-9	2 (13)
10-19	6 (38)
20-29	5 (31)
30-39	3 (19)
Comorbidities ^a	
Hypertension	12 (75)
Diabetes	2 (13)
Infections	1 (6)
Cancer	1 (6)
Other ^b	5 (31)
Length of time on dialysis (all types) ^a	
<1 year	4 (25)
1-2 years	3 (19)
3-5 years	3 (19)
>5 years	2 (13)
Not on dialysis (pre-emptive transplant)	4 (25)
Dialysis modality (N=12) ^a	
In-centre haemodialysis	6 (50)
Home haemodialysis	3 (25)
Peritoneal dialysis	3 (25)
Length of time on deceased donor waiting list (N=16) ^a	
<1 year	1 (6)
1-2 years	2 (13)
3-5 years	1 (6)
>5 years	1 (6)
Not on list	7 (44)
Received a previous kidney transplant	
Yes (deceased donor)	1 (6)
No	15 (94)

^aSelf-reported at time of first interview; ^bOther: bone disease, monoclonal gammopathy of unknown significance, osteoarthritis, wet macular degeneration, irritable bowel syndrome.

Table 3. Selected illustrative quotations

Theme	Illustrative Quotations
Donation as enacting familial responsibility for care	
	"It's a continuation of the nurturing process... I just can't let him down. I really don't want to do it, to be honest, I really wish I didn't have to do it... You can't let children die." (Female; Parent donor; T1)
	"I just can't do nothing and just sit back and watch, no. I mean that's the dynamics of my family as I like to see them... I thought, well, I've got to live with myself and if I don't offer and turn out to be able to then I'd feel less of a human being in a way." (Male; Sibling donor; T1)
	"[The doctor] came to me and went absolute ballistic. Why did I bring somebody on a cruise ship who had renal failure? He must have had this for years. I must have known about it. What was I doing?" (Female; Spousal donor; T1)
Analytical decision making to mitigate regret	
Avoiding anticipated regret and maintaining control	<p>"[X] who is the black sheep of the family, he's also likely to go on dialysis shortly. I don't think I'd ever do it [donate] for him, and that's because he doesn't look after himself in other ways... He's not the sort of person I would trust to – certainly not as much as [recipient] - would trust to look after such a gift." (Male; Parent donor; T1)</p> <p>"My husband was willing to be tested, and seriously I ran a mile from that situation. Not because he's not a wonderful man, not because I don't love him, but my fear was, imagine having a fight with your partner and he would always be able to throw back, "But I gave you my kidney." You can never win that argument, so I always had this hesitancy." (Female; Sibling recipient; T1)</p> <p>"I think if my husband gave me his kidney... I would imagine that every time if I had one glass of champagne too many or I'm carrying too much weight, he would be like, 'Oh, for God's sake, I gave you a kidney so the least you can do is look after it.'" (Female; Sibling recipient T2)</p>
Removing emotional impulsivity	<p>"It was almost certain to go ahead if they [recipient and spouse] wanted it. But then I did it [offered to donate] by email, I sent them both an email at the same time, so I wanted them to have a chance to think about it, and come to get over their initial shock... I didn't want to put them under pressure of being face-to-face, and I wanted them to have a chance to talk about it between themselves." (Male; Parent donor; T2)</p> <p>"I'm always concerned about how she's [the donor] going to come out of the operation...and I'm concerned if it all goes through and it all happens and it's all wonderful and then for some reason, the kidney fails, how she'd feel about that. I've spoken to her about it. She's comfortable with it." (Male; Sibling recipient; T1)</p>
Strengthened interpersonal ties	
Gaining a deeper appreciation among family members	<p>"It's actually made it [our relationship] stronger. It could have been really difficult but because we've done it together and everything we've done, we've done together. So all the doctors' appointments, and there have been lots, all the testing, all the information sessions everything we've done together." (Female; Spousal donor; T2)</p> <p>"I suppose we've got closer in a sense, where we communicate much more than we would've in the past. It has been generalised to other things [than the transplant]. And they see me as part of their family now, a closer family kind of thing." (Female; Sibling donor; T2)</p>
Stronger empathy for each other	<p>"I look out for her health a bit more; what she eats and things like that; I don't really say anything, but I monitor a bit. (Male, Child recipient; T2)</p> <p>"She has been sick for so long, and so when I was having all the tests done... it was such a tiny scrape on what she's done her whole life, and it really made me appreciate what she has been going through. And I like I say it was a scratch." (Female; Sibling donor; T1)</p> <p>"I think it's made us very sensitive that we're very significant to each other and I think it's made me treasure her a lot more." (Male; Spousal donor; T2)</p>
Improving social participation	<p>"It's a selfish act as well, in a way... it's giving her a better quality of life, but it's giving us a better quality of life as well, together. And we can go on normal holidays, and travel or do whatever, without any problems." (Male; Spousal donor; T1)</p> <p>"I think [post-donation] we could experience some more shared interests, like I like to walk, and I'd like to be able to walk with him, but it's a snail's pace</p>

	at the moment, so I accept that that's the way it is, so I do those on my own... but I would like us to have a fitter and well-balanced life." (Female; Spousal donor; T1)
	"I hope to get back to being more active [post-donation]. And doing more work walking and bike riding, going on holidays, and going to visit my grandchildren. And just having more energy...Take up in life where we left off really, in a way." (Female; Spousal recipient; T1)
Instability of relational impacts	
Anger and aggression threatening to dynamics	"I can't understand why he will explode about the fact that a tablet dropped on the floor and it's about the fact that he's shaking, and he can't control certain things anymore when he used to be able to control them so that's just really hard to adjust to." (Female; Spousal donor; T2) "If his personality is maybe a bit different because of the drugs that he's on, if he ends up too difficult to live with, I could leave. Well when he got sick he was on a high dosage of prednisone and he was pretty difficult then." (Female; Spousal donor; T1)
Unanticipated stress and emotional lability	"You'd think we were an unhappy married couple who are constantly fighting. That's how she's been probably for the last year due to [the transplant]. Before that, we never fought. It's got her uptight and panicking and worrying about she'd say things like she's worried she'll die on the operating table. She's a panicker, a worrier." (Male; Spousal donor; T1) "We've had a few of those [arguments]... It has tested our relationship, but he's never said, 'Well I don't want to do this,' but I have said, 'Stop it. Ring them up and tell them I don't want it. I'm not doing it.'" (Female; Spousal recipient; T1) "I've actually found that's one of the consequences of the operation. I've become more emotional... Just been getting chocked up. I nearly got chocked up then just talking to you about [my donor]." (Male; Sibling recipient; T2)
Triggering familial tension	"[My other Son], he just refused [to donate]. And that caused a lot of disharmony between us at the time. And I'll really never forget it. It's etched there indelibly because I remembered how he refused, and [the recipient], even though he's over it now, he will never forget that fact. [The recipient] was bitterly hurt by it all." (Female; Parent donor; T2) "With my sister the other day...apparently I was being selfish, and I just lost it. I got very mad, and I had to leave....The emotions involved, all the what-ifs? What if it fails after a week just wasted a bloody good kidney? Dad could have had that for another 40 years?" (Male; Recipient; T1)
Renegotiating social roles	
Unexpected continuation of caregiving responsibilities	"I think the fact that the recovery is not always 100% and it can still be a roller coaster ride as far as health goes. It has its emotional dimension and because of that it can still put strains on a relationship." (Male; Spousal donor; T2) "I've had to take the lead on that [the drug regime] because I think it all became too much for him at times. He's a little bit more confused than he was before...I don't know how he'd go if he had to do that on his own." (Female; Spousal donor; T2)
Inability to relinquish the caregiving role	"He insisted on driving me and I said, "Oh no, I can drive myself." It takes a real effort to do it [say 'no'] without being hurtful. He's was my carer while I was having dialysis because I didn't feel well enough to drive home. He's had this role of carer and I guess it's maybe hard to give up." (Female; Spousal recipient; T2) "He [the recipient] suddenly was better one day and so he said, "Well, I'm off now. I'm going out for the day, and I'll be gone," and I'll just leave you there. Well, I was a bit miffed, but at the same time...I realised that was a good thing for me, but miffed, because you go, well, you just get up and go and leave me there now." (Female; Spousal donor; T2)
Disappointment with unfulfilled renewal of intimacy	"My relationship with [recipient], well, in some cases we do have a rather difficult relationship, but I'm aware of the problems because he's become more of a carer, and that's the - it's a bit of a pity, because there's no romance. No romance or love making." (Female; Spousal recipient; T2) "As far as sex goes, I am frightened to have sex because I'm on the immunosuppressants, every time I have sex I get a urinary tract infection. And I just don't want them there, they're too horrible and so I always decline it." (Female; Spousal recipient; T2) "That [sexual problems] is so normal with what he's got, so don't worry about it,' and she [the clinician] was actually the one to say as well, she goes,

	‘Watch out when you do get your kidney, because then he’ll be like little teenager again,’ and oh yeah good. Let’s hurry this thing up now.” (Female; Spousal donor; T1)
Dissatisfaction over discrepant energy levels	<p>“I have got a whole big long list of interests there but he [recipient] doesn’t seem to have as many interests, he’s happier just to stay at home and do the gardening... I want to get out and about and be with people because I find it very stimulating and whereas he is not.” (Female; Spousal donor; T2)</p> <p>“He’s become more of a carer...where he is happy to stay home, he’d be happy to stay home the rest of his life and not go anywhere, that’s what he’s like. But I don’t want to do that. I want to get out and about and involved in things. It is difficult when one person wants to go out more and have fun and the other person doesn’t. It’s a very difficult thing in a relationship.” (Female; Spousal recipient; T2)</p>
Guilt over unmet expectations	
	<p>“But if it went wrong and you think to yourself, oh shit, she’s given me her kidney and it’s all gone pear shaped. She’s out a kidney and nothing’s been achieved. I’ve stuffed it up, my body’s stuffed it up.” (Male; Spousal recipient; T1)</p> <p>“Imagine the worst-case scenario he died on the table tomorrow. Imagine how I would feel and then having them [my family] blame me for the rest of my life.” (Male; Child recipient; T1)</p> <p>“He’s [the recipient’s] extremely depressed, with the medication. He hasn’t got a job; therefore he’s depressed. I’m disappointed for him, but whilst my donation has nothing to do with that. I’m please I gave it to him, but I think it’s going to take a little longer for him to get up on his feet, but he feels guilty about taking my kidney.” (Male; Parent donor; T2)</p>
Inevitability of the gift relationship	
Vague and transient indebtedness	<p>“Can you put a monetary figure on it? And then if you do, what is it? Is it too much? Is it not enough? Is it a servitude thing? I don’t know. I’ve written an email to [recipient] and the family to tell them what I think of her and what I think of her gift.” (Male; Sibling recipient; T1)</p> <p>“I think maybe I just do a few extra things [around the house] because I am a bit indebted. I feel that I have to be more careful with my health, because you’re carrying something precious. It’s not a really conscious thing, but it’s kind of a subconscious thing that’s there in the background. I don’t go I’m going to vacuum the whole house and do this and that, but I know I do try and help a bit more and do things.” (Male; Spousal recipient; T2)</p> <p>“It’s obviously a gift but there’s still you still have thoughts that you still are beholden to your brother. Not that he’s ever said it but you get that feeling. You can’t not have those thoughts can you when someone in the family has given you such a massive gift. There’s no sort of real issue but obviously you still think about it.” (Male; Sibling recipient; T2)</p>
Expectation of reciprocity	<p>“But I guess there’s implicitly, there’s always a sense of, understanding of what a gift implies from an obligation point of view, and I’ve tried to make that clear, from the time that we made the offer, it was understood it was an offer without any obligations. A concern I had at the time was that it might have affected our relationship, and I didn’t want it to do so, so I didn’t want any sense of obligation to be felt by the others.” (Male; Parent donor; T2)</p> <p>“I thought it the other day, there was something that happened, and I thought well, you know I’m giving him a kidney, so he really should pay for this and now I thought to myself, I shouldn’t be thinking like this but I am.” (Female; Spousal donor; T2)</p>
Transferring kidney ownership	<p>“It’s a gift. It’s his. I have no sense of it as my kidney... it’s totally his. If he decided to go binge drinking every night, I might be a little bit concerned, but I would anyway. So, yeah, that’s totally his business.” (Female; Spousal donor; T2)</p> <p>“I just feel really strongly that I gave the kidney for him so that he can live his life, whatever that means. He’s like “I don’t want to ride my motorbike because I might crash and it’s a waste of your kidney”, I’m like, “It’s a waste of your kidney if you don’t do that”, it’s not my kidney anymore.” (Female; Spousal donor)</p> <p>“I’ve been really careful to make sure that [the recipient] knows that I don’t want her to have any guilt associated with it at all. I’ve been letting her know that it’s okay to be her after the operation...if she actually wants to have a glass of wine, or if she wants to have, you know, lead a normal life.” (Female; Sibling donor; T1)</p>

T1: pre-donation/transplantation interview; T2: post-donation/transplantation interview

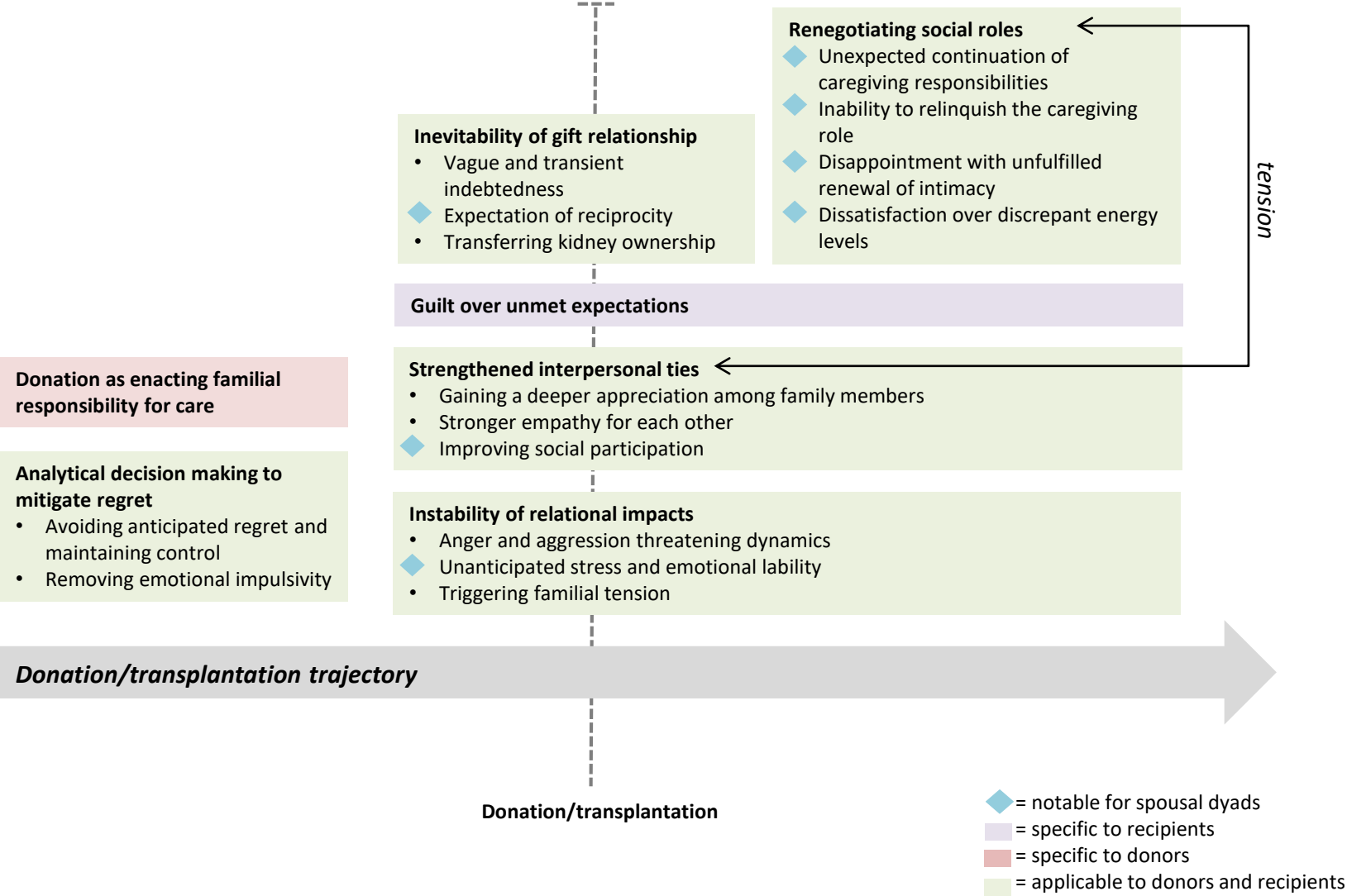
1
2 **Figure legends**
3

4 Figure 1. Thematic schema
5

6 Donors and recipients both expected and experienced a strengthened emotional connection and an improved “combined” quality of life. However, at the same
7 time, some dyads were confronted with relationship conflict and tension which were triggered or exacerbated by disappointment with unfulfilled expectations
8 of post-transplantation life, and behavioural and emotional changes. Some donors and recipients were aware of potential relationship strains such as anticipated
9 guilt and indebtedness of the recipient prior to the transplant, however some dyads were still confronted by these challenges of the one-sided “gift relationship”
10 post-donation, which affected their relationship.
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For peer review only

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Supplementary Table 1: Interview question guide**1. Time point 1 – Pre-donation: Donors**

- a. Explanation of study, obtain informed consent
- b. How did you meet and could you tell me about your relationship with X?
- c. What are three words that you would use to describe them?
- d. On a scale of 0 (not close at all) to 10 (very close), how would you rate your relationship – why?
- e. What would you say are their strengths (or what you value/respect most about them) and their weaknesses?
- f. How did first come to know that X had kidney disease? How did you come to know that they would need a transplant?
- g. How did you decide to be a donor?
- h. Did someone ask you to donate or did you offer to donate a kidney? Were there other potential donors?
- i. What was the most important motivation to donate a kidney - why?
- j. What reservations or concerns did you have and how did you overcome them?
- k. To what extent do you think your relationship with X influenced your decision – how/why?
- l. How did your relationship with other family members, friends, colleagues have an influence on your decision – how/why?
- m. How do you expect that your relationship with the recipient will change after donation? Can you give an example...?
- n. Is there anything else that you think is important to add?

2. Time point 1 – Pre-donation: Recipients

- a. Explanation of study, obtain informed consent
- b. How did you meet and could you tell me about your relationship with X?
- c. What are three words that you would use to describe them?
- d. On a scale of 0 (not close at all) to 10 (very close), how would you rate your relationship – why?
- e. What would you say are their strengths (or what you value/respect most about them) and their weaknesses?
- f. When did you find out that you had CKD? When did you find out that you needed a transplant? What was your reaction?
- g. Tell me when you were thinking about asking your donor? Were there several potential donors?
- h. What was the most important motivation to accept this kidney from a living donor and not wait for a deceased donor kidney?
- i. How do you expect that your relationship with the donor will change after donation? Can you give an example...?
- j. Is there anything else that you think is important to add?

3. Time point 2 – Post-donation: Donors and recipients

- a. How have you recovered post-surgery?
- b. What kind of thoughts have you had about the transplant?
- c. How much contact have you had with your donor/recipient over the past two weeks? Please expand.
- d. Do you think the transplant is impacting on your relationship in any way – how?
- e. Has the transplant changed the way you view your donor/recipient – how? Can you give an example?
- f. Do you think the transplant has changed the way your donor/recipient views you – how? – Can you give an example?
- g. If yes, how have you been coping with these changes? How do these changes compare with your expectations?
- h. What kinds of things have you discussed with each other about the transplant?
- i. Have you told your donor/recipient about how you have been feeling since the transplant? How did this conversation go?
- j. Did you argue or have any disagreements with your donor/recipient in the past two weeks - why? How was it resolved?
- k. What aspects of a relationship do you believe are most important to cope with the donation/transplant?
- l. Is there anything else that you think is important to add?

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	3
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5
Purpose or research question	#4 Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and	6

guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.

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14	Researcher	#6	Researchers' characteristics that may influence the	6
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17			and / or presuppositions; potential or actual interaction	
18			between researchers' characteristics and the research	
19			questions, approach, methods, results and / or	
20			transferability	
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25	Context	#7	Setting / site and salient contextual factors; rationale	6
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28	Sampling strategy	#8	How and why research participants, documents, or	6
29			events were selected; criteria for deciding when no	
30			further sampling was necessary (e.g. sampling	
31			saturation); rationale	
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35	Ethical issues pertaining	#9	Documentation of approval by an appropriate ethics	6
36	to human subjects		review board and participant consent, or explanation for	
37			lack thereof; other confidentiality and data security issues	
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40	Data collection methods	#10	Types of data collected; details of data collection	6
41			procedures including (as appropriate) start and stop	
42			dates of data collection and analysis, iterative process,	
43			triangulation of sources / methods, and modification of	
44			procedures in response to evolving study findings;	
45			rationale	
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50	Data collection	#11	Description of instruments (e.g. interview guides,	See
51	instruments and		questionnaires) and devices (e.g. audio recorders) used	note 1
52	technologies		for data collection; if / how the instruments(s) changed	
53			over the course of the study	
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57	Units of study	#12	Number and relevant characteristics of participants,	7 (and
58			documents, or events included in the study; level of	T1)
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participation (could be reported in results)

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3	Data processing	#13	6-7
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9	Data analysis	#14	6-7
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16	Techniques to enhance	#15	6-7
17	trustworthiness		
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21	Syntheses and	#16	See
22	interpretation		note 2
23			
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25			
26	Links to empirical data	#17	Table 3
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30	Intergration with prior	#18	13
31	work, implications,		
32	transferability and		
33	contribution(s) to the field		
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40	Limitations	#19	15
41			
42	Conflicts of interest	#20	2
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48	Funding	#21	2
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Author notes

1. 6 and (Supp. T1)
2. 8-12 (and Fig 1)

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2 American Medical Colleges. This checklist was completed on 12. September 2018 using
3 <http://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)
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Living kidney donor and recipient perspectives on their relationship: longitudinal semi-structured interviews

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Primary Subject Heading:	Renal medicine
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Manuscripts

Living kidney donor and recipient perspectives on their relationship: longitudinal semi-structured interviews

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14 **Running Title: Living kidney donor-recipient relationship: longitudinal interview study**
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18 **Keywords:** qualitative research, kidney donation,
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23 **Abbreviations:**
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25 U.K. United Kingdom
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27 U.S. United States
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Abstract

Background and objectives: Many donors and recipients report and improved bond post transplantation; however unexpected conflicts and tension may also occur. Insights into the lived experiences of the donor-recipient relationship can inform strategies for interventions and support. We aimed to describe donor and recipient expectations and experiences of their relationship before and after living kidney donor transplantation.

Design, setting and participants: Semi-structured interviews were conducted with 16 donor-recipient pairs before the transplant and 11-14 months post-transplant. Transcripts were analysed thematically.

Results: We identified seven themes (with respective subthemes): donation as enacting familial responsibility for care; analytical decision making to mitigate regret (avoiding anticipated regret and maintaining control, removing emotional impulsivity); strengthened interpersonal ties (gaining a deeper appreciation among family members, stronger empathy for each other, improving social participation); instability of relational impacts (anger and aggression threatening dynamics, unanticipated stress and emotional lability, triggering familial tension); renegotiating social roles (unexpected continuation of caregiving responsibilities, inability to relinquish the caregiving role, disappointment with unfulfilled renewal of intimacy, dissatisfaction over discrepant energy levels); guilt over unmet expectations; and inevitability of the gift relationship (vague and transient indebtedness, expectation of reciprocity, transferring kidney ownership).

Conclusions: Donor-recipient relationships may be improved through increased empathy, appreciation, and ability to participate in life together, however unfulfilled expectations and behavioural and emotional changes in recipients (a side effect related to immunosuppression), remain unresolved consequences of living kidney donor transplantation. Education and counselling to help donors and recipients adjust to potential changes in relationship dynamics may help protect and foster relational stability post-donation.

Article Summary

Strengths and limitations of this study

- We conducted longitudinal interviews with the same donor-recipient dyads prior to donation/transplantation then one year later and this provided access to changes in perspectives and experiences of the donor-recipient relationship in “real-time”
- We used thematic analysis to identify seven themes (and respective subthemes) and discuss their interrelationship
- All participants were English-speaking, aged 18 years and over and the majority had attained a tertiary level of education thus transferability of these findings to other contexts remains unclear

Introduction

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5 Living kidney donor transplantation confers superior survival and quality of life benefits for most patients
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7 with end-stage kidney disease compared with dialysis.¹ Rates of living kidney donor transplantation have
8
9 risen worldwide, comprising approximately 30% to 50% of all kidney transplants in high income countries,
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11 with the majority of donors being parents, spouses or siblings.²⁻⁵ While quality of life can improve for many
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13 recipients,⁶⁻⁸ donors and recipients have to renegotiate their social roles, identity and relationships.^{8 9}
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19 Living kidney donation can strengthen the donor-recipient relationship, characterised by greater perceived
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21 emotional support and a unique emotional connection.^{8 10} However, some donor-recipient dyads have
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23 reported donation-related conflict and tension, marked by feelings of rivalry, abandonment, guilt,
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25 disappointment, anger and jealousy.¹⁰⁻¹³ Poor family dynamics are associated with post-transplant
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27 depression and decreased social functioning in recipients of a living kidney donor transplant, to a greater
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29 extent than in recipients of deceased donation.¹⁴ In a recent study,¹⁵ living kidney donors prioritised the
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31 donor-recipient relationship as the fifth most important outcome of donation, even above overall life
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33 satisfaction, mortality, pain and kidney failure. Yet, there is limited data on the donor-recipient relationship.
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39 Clinicians regard evaluating the donor-recipient relationship as ethically necessary to minimise the risk of
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41 undue coercion.¹⁶ The donor-recipient relationship after donation is variable across dyads,^{8 12 17} however
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43 little is known regarding the mechanisms underlying such differences, nor how dyads perceive pathways to
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45 relationship outcomes. Most studies have focused on living kidney donor perspectives post-donation;^{8 17-19}
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47 insight into the lived experience of the donor-recipient relationship from their perspective before and after
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49 donation is limited. We aimed to collect longitudinal data on donor and recipient expectations and
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51 perspectives of their relationship in living kidney donor transplantation, which may inform strategies to
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53 mitigate risks of relationship tension and conflict and support relationship resilience, thereby contributing to
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55 improved outcomes in living kidney donor transplantation.
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Materials and methods

Participant selection

Living kidney donors and their recipients were recruited by transplant coordinators and nephrologists from three transplant units in Sydney, Australia. They were purposively selected to ensure a range of demographic (including age, gender, donor relationship) and clinical (including dialysis modality, comorbidities) characteristics. Participant pairs were eligible if they comprised a spousal, sibling, or parent living kidney donor (as approximately 70 percent of live donations in the U.S., Canada, Australia and New Zealand are from spouses or biologically related donors^{2 4 20}) and a recipient with a confirmed transplant date. All participants had to be English speaking, over 18 years of age, and able to give written informed consent. Western Sydney Local Health District (LHD), Sydney LHD and South-Eastern Sydney LHD approved the study.

Data collection

The interview guide was developed based on a systematic review of donor-recipient perspectives¹⁰ and investigator input (Supplementary File 1). One author (A.F.R) contacted consenting participants via phone (up to three attempts) and/or email to schedule an interview. A.F.R conducted two longitudinal, individual semi-structured interviews with each participant individually, during the month prior to their donation/transplant, and 11-14 months post-donation/transplant. The interviews were conducted face-to-face in their home, office or dialysis unit, or via telephone if this was not possible. A.F.R was not previously known to participants, not involved in their clinical care. Participant recruitment ceased when theoretical saturation was reached (i.e. no new concepts were raised in subsequent interviews). Interviews averaged thirty minutes in duration and were audio-taped and transcribed.

Analysis

1
2 Using the principles of grounded theory²¹ and thematic analysis,²² A.F.R read through the transcripts and
3 inductively identified preliminary concepts. The transcripts were entered into data management software
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5 HyperRESEARCH (ResearchWare Inc, United States, Version 3.7.3) where A.F.R reviewed the transcripts
6
7 line-by-line (by dyads) and coded emerging concepts. A.F.R and A.T met frequently to refine the coding
8
9 structure. The emergent findings across all dyads were compared. Similar concepts were grouped into
10
11 themes, and patterns between themes and subthemes were identified and mapped into a thematic schema. As
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13 a form of investigator triangulation, authors T.G, C.S.H and A.J also read the transcripts and reviewed the
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15 themes to ensure that the findings reflect the full range and depth of the data and enhance the analytical
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17 framework.
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25 *Patient and public involvement*

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30 The donor-recipient relationship has been identified as a research priority by patients,²³ however patients
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32 were not involved in the design of this study. On publication of this manuscript, a summary of the study
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34 results was disseminated back to participants.
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39 **Results**

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44 Of the 28 donor-recipient pairs approached, 16 pairs participated. Reasons for non-participation included
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46 lack of time and avoiding the risk of jeopardising the stability of their relationship prior to the transplant.
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48 From October 2014 to June 2017, we conducted 32 pre-transplant interviews (16 donors, 16 recipients) and
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50 29 post-transplant interviews (14 donors, 15 recipients). One pair was excluded from the post-donation
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52 interviews as the recipient received a deceased donor kidney, and one donor could not be contacted for the
53
54 second interview. The characteristics of participants are shown in Tables 1 and 2. Nine (56%) donors and 11
55
56 (69%) recipients were male. Eight (50%) were spousal dyads in which four donors were female, five (31%)
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1 were sibling pairs, and three (19%) were parent-child dyads. On average, each interview was 30 minutes in
2 duration, and 53 (87%) interviews were conducted in-person.
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7 We identified seven themes: donation as enacting familial responsibility for care, analytical decision making
8 to mitigate regret, strengthened interpersonal ties, instability of relational impact, renegotiating social roles,
9 guilt over unmet expectations; and inevitability of the gift relationship. The subthemes are described below,
10 and quotations to illustrate each theme are provided in Table 3. Figure 1 depicts a conceptual schema of the
11 relationships among themes.
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23 **Analytical decision making to mitigate regret**

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28 *Avoiding anticipated regret and maintaining control:* Some participants took into account tension,
29 decisional regret and feelings of guilt when making decisions about donating or accepting a kidney.
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31 Recipients refused to accept donations from family members who they anticipated would use it against them
32 in the future to ‘control situations’ such as to win arguments, to make them change behaviours (e.g. drinking
33 alcohol) or in a potential divorce settlement. Some donors did not want to regret donating and therefore did
34 not want to donate to recipients who they perceived had either “contributed to [their] own kidney problems”
35 (e.g. through excessive drinking) or had disappointed or hurt them as they did not “trust them to look after
36 such a gift”.
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48 *Removing emotional impulsivity:* To preserve the stability of their relationship, some participants
49 approached their decision pragmatically. Some donor-recipient pairs communicated about all possible
50 relationship consequences, including divorce, to ensure they were able to accept these risks. One donor
51 completed his work-up without the knowledge of the recipient and then communicated his offer of donation
52 via e-mail to allow the recipient “a chance to absorb it” so they would not feel obligated to respond
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1 immediately. The donor outlined a logical case for why he should be the donor and emphasised that the offer
2 was “without strings” to minimise potential disruption to their relationship.
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7 **Donation as enacting familial responsibility for care**

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11 Some donors viewed donation as a ‘continuation of the nurturing process’ for their family member, and this
12 was intensified in mothers and wives. Some felt somewhat at fault for their recipient’s illness and felt
13 compelled to donate. One mother felt “a little bit responsible [for her son’s kidney disease] that we didn’t
14 have him checked out.” Another donor reported that their clinician went “absolutely ballistic” at her for not
15 knowing that her spouse had kidney failure (prior to diagnosis). Some donors believed they would endure
16 unbearable guilt if they did not take care of their family by donating a kidney.
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28 **Strengthened interpersonal ties**

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32 *Gaining a deeper appreciation among family members:* While some participants believed their relationship
33 did not change post-transplant, others felt they developed an intangible “special bond” and became closer
34 through increased contact. Spousal dyads felt they had “seen the worst and best bits” of each other through
35 the “difficult process” of donation and become stronger and more honest with each other. Some spousal
36 dyads viewed the commitment of donation akin to marriage and became more aware of how their partner
37 “treasured them”. Some donors felt that their recipient’s family members displayed a “warmer attitude” and
38 gratitude towards them.
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51 *Stronger empathy for each other:* Some donors and recipients became more focused on each other’s
52 wellbeing than their own. For some donors, the clinical workup was their first experience of undergoing
53 medical tests and waiting in hospitals and they gained a newfound appreciation of the discomfort,
54 uncertainty and inconvenience their recipient had experienced in hospital. Recipients viewed their donor as
55 ‘brave’ but held concerns about their donor’s health (e.g. kidney function, fatigue, potential cancers).
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3 *Improving social participation:* Spousal pairs anticipated that recipients would have increased energy to
4 participate in activities after transplant, giving them “a better life together”. They looked forward to being
5 able to do activities together including travelling, walking, bike riding, going to the beach and dancing. For
6
7 some pairs, these expectations were realised and they felt “happier” and “stronger” as a couple.
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14 **Instability of relational impacts**

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18 *Anger and aggression threatening dynamics:* Both donors and recipients worried about the potential impact
19 of steroid medication (in particular, prednisone) on the recipient’s ‘personality’ and how this could affect
20 their relationship. Recipients were concerned that they “would not be the same person” on medication, and
21 they may become angry, depressed, “grumpy and moody” towards their partner. One spousal donor was
22 worried that she may leave her recipient if “he ends up too difficult to live with”. After the transplant,
23 donors felt stressed in having to cope with the anger and irritability experienced by their recipient – “like
24 waiting for a ticking time bomb to go off”.
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37 *Unanticipated stress and emotional lability:* The upcoming transplant was a priority and consumed the time
38 and energy of some spousal pairs who experienced increased tension and arguments, which they attributed
39 to the stress of the donation process (e.g. uncertainty regarding donor eligibility and waiting for transplant
40 confirmation) and upcoming surgery. After donation, some recipients experienced exaggerated changes in
41 mood and/or a reoccurrence of previous mental health disorders (including depression and bipolar disorders)
42 which they believed were due to the stress, adjustment and steroids, and which affected their relationship.
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53 *Triggering familial tension:* For some, in particular parent-to-child dyads, the donation became a source of
54 stress in their relationships with other family members. Recipients experienced “snide comments” from and
55 arguments with other family members (e.g. sibling, other parent or parent-in-law) who did not agree or were
56 concerned for the donor. Such recipients felt this compounded their feelings of guilt and worry about the
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1 transplant. Donors and recipients also noted friction in their relationships with other family members who
2 did not offer to donate. Some donors believed the donation triggered arguments within the extended family
3 who challenged the donor's motives and instigated family discussion of the Will of the recipient, especially
4 in blended families.
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11 **Renegotiating social roles**

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16 *Unexpected continuation of caregiving responsibilities:* Spousal donors expected their role as a 'caregiver'
17 to diminish post-transplant. For some donors whose recipient had complications and side effects (e.g. BK
18 virus, diabetes), they were disappointed in having to still bear caregiving responsibilities. They described
19 recovery as a "rollercoaster" which required them to exercise tolerance and patience towards their recipient.
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27 *Inability to relinquish the caregiving role:* Some spousal recipients felt their donors wanted to continue
28 caring for them post-transplant and were worried about hurting their donor's feelings by informing them that
29 they no longer required their assistance such as being driven to attend follow up clinic. One spousal donor
30 was offended when their recipient began to do activities alone (e.g. shopping, exercise), which they had
31 normally done together.
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41 *Disappointment with unfulfilled renewal of intimacy:* Some spousal pairs eagerly anticipated improved
42 physical affection and intimacy post-transplant, with one donor citing this as the primary reason for her
43 donation. Recipients reported that clinicians advised them that increased libido was a side effect of steroid
44 medication. However, some recipients were afraid to have intercourse whilst on immunosuppressants as this
45 could result in urinary tract infections. For other recipients, intercourse was painful, or they did not
46 experience increased libido. Some recipients did experience an increased libido but became frustrated when
47 this was not matched by a similar change in their spousal donor. Recipients were reluctant to discuss their
48 sexual concerns with their clinicians as they believed this would be regarded as peripheral to the primary
49 focus on their health.
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3 *Dissatisfaction over discrepant energy levels:* In some spousal pairs, the recipient's vitality increased and
4 surpassed that of their donor, shifting the relationship dynamic and causing relationship tension as the
5 recipient wanted to engage in activities (e.g. running, dancing, socialising) they had enjoyed prior to
6 becoming unwell and to lead a more fast-paced and active lifestyle than their partner. Conversely, when
7 recipients did not experience their expected 'boost' in vigour, donors felt disappointed and frustrated that
8 they were unable to engage in their desired shared lifestyle.
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18 **Guilt over unmet expectations**

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23 Before the transplant, recipients worried that if their desired physical, psychological and social
24 improvements were not achieved after the operation, they may feel regret and be blamed by others for
25 accepting the kidney donation. Some recipients, despite having a successful transplant, did not feel "stronger
26 and better", often due to comorbidities e.g. diabetes. Such recipients felt they had failed their donors, were
27 "wasting" their donor's kidney and efforts, and worried they would be blamed by their donor or other family
28 members.
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39 **Inevitability of the gift relationship**

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44 *Vague and transient indebtedness:* Recipients were "eternally grateful" to their donor and felt indebted to
45 them, however this was "a subconscious thing" and "not a real issue" and diminished over time. They
46 believed the best way to show their appreciation was to look after their health and verbally thank the donor.
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53 *Expectation of reciprocity:* Some spousal donors felt disgruntled that their recipient was not more openly
54 appreciative of them. This mainly occurred when the donor was frustrated with their recipient, for example,
55 for not supporting them in a family argument, not paying for something, or if they believed they were not
56 making an effort in their relationship. However, donors felt uneasy and guilty about having such thoughts.
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2 *Transferring kidney ownership:* Donors were conscious that the imbalance of the one-way gift had the
3 potential to cause unease in their relationship and did not want their recipient to feel guilty. They
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5 conceptualised the kidney as a gift and were careful about how they discussed the kidney in front of the
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7 recipient and encouraged their recipient to participate in physical activities and not to be overly cautious.
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9 Donors and recipients recalled being told by clinicians “once it’s out of you it’s not yours anymore”. Whilst
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11 some donors were initially anxious about the recipient’s health and wanted to “wrap them in cotton wool”,
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13 this lessened over time; they emphasised they had donated so their recipient could live life to the full.
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23 Discussion

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27 For donors and recipients, improved and strengthened relationships after living kidney donor transplantation
28 were marked by increased closeness and appreciation of each other, stronger empathy, more frequent
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30 contact, and enhanced quality of life as a pair. At the same time, some dyads were confronted with conflict
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32 and tension triggered or exacerbated by behavioural and emotional changes (anger, aggression, alterations in
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34 mood in recipients related to steroid use), and disappointment with unfulfilled expectations of recovery of
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36 health, re-establishing roles, and renewal of intimacy. Some donors and recipients were aware of potential
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38 relational strains such as anticipated guilt and indebtedness of the recipient and changes in relationship
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40 dynamics because of the one-sided ‘gift relationship’ and donors emphasised that recipients should not feel
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42 any obligation or be overly cautious.
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51 There were differences in the expectations and experiences of spousal dyads when compared with parent-
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53 child and sibling pairs. Spousal pairs expected that the donation/transplant would enhance overall quality of
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55 life as a couple, which is in accordance with previous research^{9 11 24} and reflected by the recent in donor
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57 assessment from considering the risks to the donor and benefits to the recipient at an individual level, toward
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59 a decision-making model that combines risks and benefits for “interdependent donors” (donors residing in
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1 the same household as their recipient.²⁵ For some donors, enhanced combined quality of life was a key
2 motivation for donating a kidney, which may explain why spousal couples in our study were focussed on
3 psychosocial impacts of living kidney donor transplantation. This finding is in accordance with previous
4 research whereby related donors prioritised psychosocial outcomes, namely the donor-recipient relationship
5 and family life.¹⁵ Any unmet expectations of retaining a caregiver role (for donors), improved social life,
6 and increased intimacy caused disappointment and frustration in the donor-recipient relationship. Spousal
7 pairs also reported increased tension and arguments prior to the transplant. The donor in the spousal dyad
8 has multiple and simultaneous roles in the relationship – caregiver, spouse and kidney donor; and we
9 speculate that this comprised an additional stressor on the donor-recipient relationship. Further, spousal
10 donor candidates have reported feeling more responsible for the recipient's health post-donation, again
11 likely due to their multiple roles.²⁶ With the spousal donor and recipient undergoing workup for transplant
12 together, this process became a priority in their life and led to increased tension and disruption. Previous
13 research has found that spousal donors (when compared with genetically related donors) expect longer
14 recovery times, more psychological problems and more pain and discomfort associated with surgery and
15 recovery,²⁶ possibly compounding the experienced pre-donation stress. However, some spousal dyads felt
16 that going through the donation process bolstered resilience in their relationship.

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39 Sibling pairs, when compared with spousal and parent-child dyads, seemed to be more analytical in their
40 approach to decision making regarding donation with an acute awareness of the imbalance in the power
41 dynamics due to the one-way gift. All sibling recipients in our study were either married and/or resided in
42 another state to their donor, thus, unlike spousal and parent donors, the donor was less present in the
43 recipient's day-to-day life and did not hold a caregiving role. This finding provides a more nuanced picture
44 and extends previous research that has found that related donors with close relationships to their recipients
45 give less consideration to the risks of donation and their long term health outcomes than those who with
46 more distant relationships.²⁷

1 Donor-recipient pairs felt unprepared and unable to manage side-effects of immunosuppression, in
2 particular, irritability and aggression. While the adverse effects of immunosuppressants (particularly
3 steroids) on behaviour and mood have been well-established,^{28 29} little attention has been paid to behavioural
4 strategies to assist patients and their families with such effects. In severe cases, recipients may be prescribed
5 mood altering and stabilising medications (e.g. antidepressants, antipsychotics and anti-anxiety
6 medication)³⁰ however evidence for this is limited to case studies and pilot studies.³¹⁻³³ Donors and
7 recipients were also reluctant to discuss problems with their mood and sexual difficulties with their clinical
8 team as they believed they did not have enough time to talk about issues secondary to the kidney. However,
9 sexual problems have been reported in over 60% of renal transplant recipients^{34 35} and have been strongly
10 correlated with decreased quality of life up to five years post-transplant.³⁴

11 Studies have shown that unrealised expectations of donors and/or recipients of life post transplantation,
12 contributed to difficulties in their relationship.¹⁰ For example, donors and/or recipients were disappointed
13 that transplantation had not led to the desired level of improvement in physical and emotional participation
14 in family life. Whilst our study confirms these previous findings we also found that in some spousal couples,
15 functioning (e.g. energy levels, libido and level of independence) improved in recipients, and surpassed that
16 of their donor, which led to tension in the donor-recipient relationship. In spousal dyads, it is common that
17 the illness has become completely embedded in their relationship and identities, with an enforced imbalance
18 of power and lack of independence in relational roles due to the illness.³⁶ Successful transplantation
19 represents a milestone where both patient and spouse must communicate effectively and re-establish healthy
20 boundaries and identities.

21 We conducted longitudinal interviews with the same dyads prior to donation/transplantation then one year
22 later and this provided access to changes in perspectives and experiences in “real-time,” potentially allowing
23 more accurate recall of events and reflections.³⁷ This also enabled stronger rapport and thus participants may
24 have been more willing to disclose their perspectives more openly. We used purposive sampling to capture a
25 relatively diverse cross-section of donor-recipient dyads.

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3 However, there are potential study limitations. Some donors/recipients refused to participate to avoid the
4 risk of disturbing the stability of their relationship prior to the transplant, thus transferability of these
5 findings to those with such insecurities about their relationship remains unclear. All participants were
6 English-speaking, over 18 years of age and the majority had attained a tertiary level of education. While this
7 reflects the majority of the donor population in Australia, the transferability of these findings to other
8 populations and contexts is uncertain. Additionally, donor-recipient dyads where the recipient is under 18
9 years of age may have unique experiences not captured in this study. Of note, in Australia, donors must be
10 of legal age (18 years) to be a living donor. We suggest that future research includes other donor-recipient
11 relationships (e.g. parents and non-adult children, friends, aunts, uncles) given the rise of other types of
12 donor-recipient relationships in countries such as the United States {Organ procurement and Transplantation
13 Network, 2018 #505}.

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30 Our study draws attention to the need for interventions and support for donors and recipients to manage
31 mood changes of recipients; tensions arising from the gift relationship; and adjustment of the identity and
32 roles post-transplant. We recommend incorporating education on strategies to cope with emotional lability
33 for both recipients and family members prior to transplantation. Additionally, this should be included in the
34 post-donation psychosocial review in the first year post-transplant for both recipients and donors with
35 referral to a psychiatrist if indicated.³⁸ Psychological services can assist both recipients and donors with
36 coping with recipient's emotional lability through acceptance strategies, normalisation, behavioural
37 strategies, improved communication and problem-solving abilities.³⁹ Education both pre- and post-transplant
38 regarding the nature of the one-way gift relationship may help donors and recipients have a functional
39 conceptualisation of the gift and ensure recipients are not overwhelmed by feelings of guilt.⁴⁰ Facilitating
40 access to relationship counselling in the first year post-transplant may assist spousal couples struggling with
41 unmet expectations and adjustment in relational roles and identity post-transplantation.³⁶

1 While living kidney donor guidelines⁴¹⁻⁴⁷ recommend assessment of the donor-recipient relationship and
2 post-transplant expectations, guidelines for transplant recipients do not explicitly address this. Guidelines
3 recommend psychosocial follow-up of both donors and recipients, however the donor-recipient relationship
4 is not specifically addressed. Whilst some transplant centres administer quality of life measures (e.g. Short
5 Form 36) to review the psychosocial health and wellbeing in post-donation follow-up care,^{48 49} many of
6 these measures do not contain questions pertaining to sexual functioning and/or satisfaction and recipient
7 mood changes, which were highly important to donors and recipients, who were hesitant to discuss these
8 with clinicians. This calls for a need to include these domains in patient/donor-reported outcome measures.

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21 In summary, living kidney donation can strengthen donor-recipient relationships, but for some pairs, may
22 also trigger unexpected conflict and tension and disappointment with unfulfilled expectations. Interventions
23 to address potential relationship difficulties are needed. In terms of post-transplant follow up, assessment of
24 the donor-recipient relationship requires discussion about adjustment in relational roles and relationship
25 dynamics, changes in emotional lability and sexual functioning, and donors/recipients should have access to
26 psychological services when required. A more comprehensive focus on protecting and supporting donor-
27 recipient relationships may contribute to overall improved psychosocial outcomes and satisfaction in living
28 kidney donor transplantation.

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10 participated in the research design, data analysis, and contributed to manuscript writing. GW, SC, GL, PB,
11 JCC, participated in the research design and provided intellectual input on the manuscript and contributed to
12 manuscript writing.
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21 **Data sharing statement:** No additional data are available.
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Table 1. Demographic characteristics of the participants (Total N=32)

Characteristics	Donors n (%)	Recipients n (%)	Total n (%)
Gender			
Male	9 (56)	11 (69)	20 (64)
Female	7 (44)	5 (32)	12 (38)
Country of origin			
Australia	12 (75)	14 (88)	26 (81)
Other ^a	4 (25)	2 (13)	6 (19)
Age (years)			
20-39	1 (6)	1 (6)	3 (9)
40-49	4 (25)	6 (38)	9 (28)
50-59	5 (32)	3 (19)	8 (25)
60-69	3 (19)	5 (32)	8 (25)
70-79	3 (19)	1 (6)	4 (13)
Ethnicity			
Anglo Celtic	13 (81)	13 (81)	26 (81)
Other European	2 (13)	2 (13)	4 (13)
Aboriginal	1 (6)	1 (6)	2 (6)
Highest level of education			
Secondary	4 (25)	6 (38)	10 (31)
Tertiary – certificate/diploma	3 (19)	3 (19)	6 (19)
Tertiary – undergraduate degree	6 (38)	4 (25)	10 (31)
Tertiary – postgraduate degree	3 (19)	3 (19)	6 (19)
Religion			
Christianity	8 (50)	12 (75)	20 (63)
No religion	7 (44)	3 (19)	10 (31)
Buddhism	0 (0)	1 (6)	1 (3)
Other	1 (6)	0 (0)	1 (3)
Employment status^b			
Full time	5 (32)	9 (57)	14 (44)
Part time/casual	4 (25)	1 (6)	5 (16)
Retired/Pensioner	6 (38)	4 (25)	10 (31)
Not employed	0 (0)	2 (13)	2 (6)
Marital status			
Married/De-facto relationship	13 (81)	12 (75)	25 (78)
Divorced/separated	2 (13)	2 (13)	4 (13)
Single	1 (6)	2 (13)	3 (9)

^aOther includes: Greece, New Zealand, The Netherlands, Zambia, Zimbabwe; ^bN =31 as one participant did not provide data

Table 2. Clinical characteristics of the recipients (n=16)

Characteristics	n (%)
Relationship to donor	
Wife/female spouse	4 (25)
Husband/male spouse	4 (25)
Son/son-in-law	3 (19)
Brother	3 (19)
Sister	2 (13)
Time since diagnosis of kidney disease (years) ^a	
1-9	2 (13)
10-19	6 (38)
20-29	5 (31)
30-39	3 (19)
Comorbidities ^a	
Hypertension	12 (75)
Diabetes	2 (13)
Infections	1 (6)
Cancer	1 (6)
Other ^b	5 (31)
Length of time on dialysis (all types) ^a	
<1 year	4 (25)
1-2 years	3 (19)
3-5 years	3 (19)
>5 years	2 (13)
Not on dialysis (pre-emptive transplant)	4 (25)
Dialysis modality (N=12) ^a	
In-centre haemodialysis	6 (50)
Home haemodialysis	3 (25)
Peritoneal dialysis	3 (25)
Length of time on deceased donor waiting list (N=16) ^a	
<1 year	1 (6)
1-2 years	2 (13)
3-5 years	1 (6)
>5 years	1 (6)
Not on list	7 (44)
Received a previous kidney transplant	
Yes (deceased donor)	1 (6)
No	15 (94)

^aSelf-reported at time of first interview; ^bOther: bone disease, monoclonal gammopathy of unknown significance, osteoarthritis, wet macular degeneration, irritable bowel syndrome.

Table 3. Selected illustrative quotations

Theme	Illustrative Quotations
Donation as enacting familial responsibility for care	
	<p>"It's a continuation of the nurturing process... I just can't let him down. I really don't want to do it, to be honest, I really wish I didn't have to do it.... You can't let children die." (Female; Parent donor; T1)</p> <p>"I just can't do nothing and just sit back and watch, no. I mean that's the dynamics of my family as I like to see them... I thought, well, I've got to live with myself and if I don't offer and turn out to be able to then I'd feel less of a human being in a way." (Male; Sibling donor; T1)</p> <p>"[The doctor] came to me and went absolute ballistic. Why did I bring somebody on a cruise ship who had renal failure? He must have had this for years. I must have known about it. What was I doing?" (Female; Spousal donor; T1)</p>
Analytical decision making to mitigate regret	
Avoiding anticipated regret and maintaining control	<p>"[X] who is the black sheep of the family, he's also likely to go on dialysis shortly. I don't think I'd ever do it [donate] for him, and that's because he doesn't look after himself in other ways... He's not the sort of person I would trust to – certainly not as much as [recipient] - would trust to look after such a gift." (Male; Parent donor; T1)</p> <p>"My husband was willing to be tested, and seriously I ran a mile from that situation. Not because he's not a wonderful man, not because I don't love him, but my fear was, imagine having a fight with your partner and he would always be able to throw back, "But I gave you my kidney." You can never win that argument, so I always had this hesitancy." (Female; Sibling recipient; T1)</p> <p>"I think if my husband gave me his kidney... I would imagine that every time if I had one glass of champagne too many or I'm carrying too much weight, he would be like, 'Oh, for God's sake, I gave you a kidney so the least you can do is look after it.'" (Female; Sibling recipient T2)</p>
Removing emotional impulsivity	<p>"It was almost certain to go ahead if they [recipient and spouse] wanted it. But then I did it [offered to donate] by email, I sent them both an email at the same time, so I wanted them to have a chance to think about it, and come to get over their initial shock... I didn't want to put them under pressure of being face-to-face, and I wanted them to have a chance to talk about it between themselves." (Male; Parent donor; T2)</p> <p>"I'm always concerned about how she's [the donor] going to come out of the operation...and I'm concerned if it all goes through and it all happens and it's all wonderful and then for some reason, the kidney fails, how she'd feel about that. I've spoken to her about it. She's comfortable with it." (Male; Sibling recipient; T1)</p>
Strengthened interpersonal ties	
Gaining a deeper appreciation among family members	<p>"It's actually made it [our relationship] stronger. It could have been really difficult but because we've done it together and everything we've done, we've done together. So all the doctors' appointments, and there have been lots, all the testing, all the information sessions everything we've done together." (Female; Spousal donor; T2)</p> <p>"I suppose we've got closer in a sense, where we communicate much more than we would've in the past. It has been generalised to other things [than the transplant]. And they see me as part of their family now, a closer family kind of thing." (Female; Sibling donor; T2)</p>
Stronger empathy for each other	<p>"I look out for her health a bit more; what she eats and things like that; I don't really say anything, but I monitor a bit. (Male, Child recipient; T2)</p> <p>"She has been sick for so long, and so when I was having all the tests done... it was such a tiny scrape on what she's done her whole life, and it really made me appreciate what she has been going through. And I like I say it was a scratch." (Female; Sibling donor; T1)</p> <p>"I think it's made us very sensitive that we're very significant to each other and I think it's made me treasure her a lot more." (Male; Spousal donor; T2)</p>
Improving social participation	<p>"It's a selfish act as well, in a way... it's giving her a better quality of life, but it's giving us a better quality of life as well, together. And we can go on normal holidays, and travel or do whatever, without any problems." (Male; Spousal donor; T1)</p>

1		"I think [post-donation] we could experience some more shared interests, like I like to walk, and I'd like to be able to walk with him, but it's a snail's pace at the moment, so I accept that that's the way it is, so I do those on my own... but I would like us to have a fitter and well-balanced life." (Female; Spousal donor; T1)
2		
3		"I hope to get back to being more active [post-donation]. And doing more work walking and bike riding, going on holidays, and going to visit my grandchildren. And just having more energy...Take up in life where we left off really, in a way." (Female; Spousal recipient; T1)
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6	Instability of relational impacts	
7	Anger and aggression threatening to dynamics	"I can't understand why he will explode about the fact that a tablet dropped on the floor and it's about the fact that he's shaking, and he can't control certain things anymore when he used to be able to control them so that's just really hard to adjust to." (Female; Spousal donor; T2)
8		"If his personality is maybe a bit different because of the drugs that he's on, if he ends up too difficult to live with, I could leave. Well when he got sick he was on a high dosage of prednisone and he was pretty difficult then." (Female; Spousal donor; T1)
9	Unanticipated stress and emotional lability	"You'd think we were an unhappy married couple who are constantly fighting. That's how she's been probably for the last year due to [the transplant]. Before that, we never fought. It's got her uptight and panicking and worrying about she'd say things like she's worried she'll die on the operating table. She's a panicker, a worrier." (Male; Spousal donor; T1)
10		"We've had a few of those [arguments]... It has tested our relationship, but he's never said, 'Well I don't want to do this,' but I have said, 'Stop it. Ring them up and tell them I don't want it. I'm not doing it.'" (Female; Spousal recipient; T1)
11		"I've actually found that's one of the consequences of the operation. I've become more emotional... Just been getting chocked up. I nearly got chocked up then just talking to you about [my donor]." (Male; Sibling recipient; T2)
12	Triggering familial tension	"[My other Son], he just refused [to donate]. And that caused a lot of disharmony between us at the time. And I'll really never forget it. It's etched there indelibly because I remembered how he refused, and [the recipient], even though he's over it now, he will never forget that fact. [The recipient] was bitterly hurt by it all." (Female; Parent donor; T2)
13		"With my sister the other day...apparently I was being selfish, and I just lost it. I got very mad, and I had to leave....The emotions involved, all the what-ifs? What if it fails after a week just wasted a bloody good kidney? Dad could have had that for another 40 years?" (Male; Recipient; T1)
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25	Renegotiating social roles	
26	Unexpected continuation of caregiving responsibilities	"I think the fact that the recovery is not always 100% and it can still be a roller coaster ride as far as health goes. It has its emotional dimension and because of that it can still put strains on a relationship." (Male; Spousal donor; T2)
27		"I've had to take the lead on that [the drug regime] because I think it all became too much for him at times. He's a little bit more confused than he was before...I don't know how he'd go if he had to do that on his own." (Female; Spousal donor; T2)
28	Inability to relinquish the caregiving role	"He insisted on driving me and I said, "Oh no, I can drive myself." It takes a real effort to do it [say 'no'] without being hurtful. He's was my carer while I was having dialysis because I didn't feel well enough to drive home. He's had this role of carer and I guess it's maybe hard to give up." (Female; Spousal recipient; T2)
29		"He [the recipient] suddenly was better one day and so he said, "Well, I'm off now. I'm going out for the day, and I'll be gone," and I'll just leave you there. Well, I was a bit miffed, but at the same time...I realised that was a good thing for me, but miffed, because you go, well, you just get up and go and leave me there now." (Female; Spousal donor; T2)
30	Disappointment with unfulfilled renewal of intimacy	"My relationship with [recipient], well, in some cases we do have a rather difficult relationship, but I'm aware of the problems because he's become more of a carer, and that's the - it's a bit of a pity, because there's no romance. No romance or love making." (Female; Spousal recipient; T2)
31		"As far as sex goes, I am frightened to have sex because I'm on the immunosuppressants, every time I have sex I get a urinary tract infection. And I just don't want them there, they're too horrible and so I always decline it." (Female; Spousal recipient; T2)
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1		"That [sexual problems] is so normal with what he's got, so don't worry about it,' and she [the clinician] was actually the one to say as well, she goes,
2		'Watch out when you do get your kidney, because then he'll be like little teenager again,' and oh yeah good. Let's hurry this thing up now." (Female;
3		Spousal donor; T1)
4	Dissatisfaction over	"I have got a whole big long list of interests there but he [recipient] doesn't seem to have as many interests, he's happier just to stay at home and do
5	discrepant energy	the gardening... I want to get out and about and be with people because I find it very stimulating and whereas he is not." (Female; Spousal donor; T2)
6	levels	"He's become more of a carer...where he is happy to stay home, he'd be happy to stay home the rest of his life and not go anywhere, that's what he's
7		like. But I don't want to do that. I want to get out and about and involved in things. It is difficult when one person wants to go out more and have fun and
8		the other person doesn't. It's a very difficult thing in a relationship." (Female; Spousal recipient; T2)
9	Guilt over unmet expectations	
10		"But if it went wrong and you think to yourself, oh shit, she's given me her kidney and it's all gone pear shaped. She's out a kidney and nothing's been achieved. I've stuffed it
11		up, my body's stuffed it up." (Male; Spousal recipient; T1)
12		"Imagine the worst-case scenario he died on the table tomorrow. Imagine how I would feel and then having them [my family] blame me for the rest of my life." (Male; Child
13		recipient; T1)
14		"He's [the recipient's] extremely depressed, with the medication. He hasn't got a job; therefore he's depressed. I'm disappointed for him, but whilst my donation has nothing to do
15		with that. I'm please I gave it to him, but I think it's going to take a little longer for him to get up on his feet, but he feels guilty about taking my kidney." (Male; Parent donor; T2)
16		
17	Inevitability of the gift relationship	
18	Vague and transient	"Can you put a monetary figure on it? And then if you do, what is it? Is it too much? Is it not enough? Is it a servitude thing? I don't know. I've written
19	indebtedness	an email to [recipient] and the family to tell them what I think of her and what I think of her gift." (Male; Sibling recipient; T1)
20		"I think maybe I just do a few extra things [around the house] because I am a bit indebted. I feel that I have to be more careful with my health, because
21		you're carrying something precious. It's not a really conscious thing, but it's kind of a subconscious thing that's there in the background. I don't go I'm
22		going to vacuum the whole house and do this and that, but I know I do try and help a bit more and do things." (Male; Spousal recipient; T2)
23		"It's obviously a gift but there's still you still have thoughts that you still are beholden to your brother. Not that he's ever said it but you get that feeling.
24		You can't not have those thoughts can you when someone in the family has given you such a massive gift. There's no sort of real issue but obviously
25		you still think about it." (Male; Sibling recipient; T2)
26		
27	Expectation of	"But I guess there's implicitly, there's always a sense of, understanding of what a gift implies from an obligation point of view, and I've tried to make that
28	reciprocity	clear, from the time that we made the offer, it was understood it was an offer without any obligations. A concern I had at the time was that it might have
29		affected our relationship, and I didn't want it to do so, so I didn't want any sense of obligation to be felt by the others." (Male; Parent donor; T2)
30		"I thought it the other day, there was something that happened, and I thought well, you know I'm giving him a kidney, so he really should pay for this
31		and now I thought to myself, I shouldn't be thinking like this but I am." (Female; Spousal donor; T2)
32	Transferring kidney	"It's a gift. It's his. I have no sense of it as my kidney... it's totally his. If he decided to go binge drinking every night, I might be a little bit concerned, but I
33	ownership	would anyway. So, yeah, that's totally his business." (Female; Spousal donor; T2)
34		"I just feel really strongly that I gave the kidney for him so that he can live his life, whatever that means. He's like "I don't want to ride my motorbike
35		because I might crash and it's a waste of your kidney", I'm like, "It's a waste of your kidney if you don't do that", it's not my kidney anymore." (Female;
36		Spousal donor)
37		"I've been really careful to make sure that [the recipient] knows that I don't want her to have any guilt associated with it at all. I've been letting her know
38		that it's okay to be her after the operation...if she actually wants to have a glass of wine, or if she wants to have, you know, lead a normal life." (Female;
39		Sibling donor; T1)

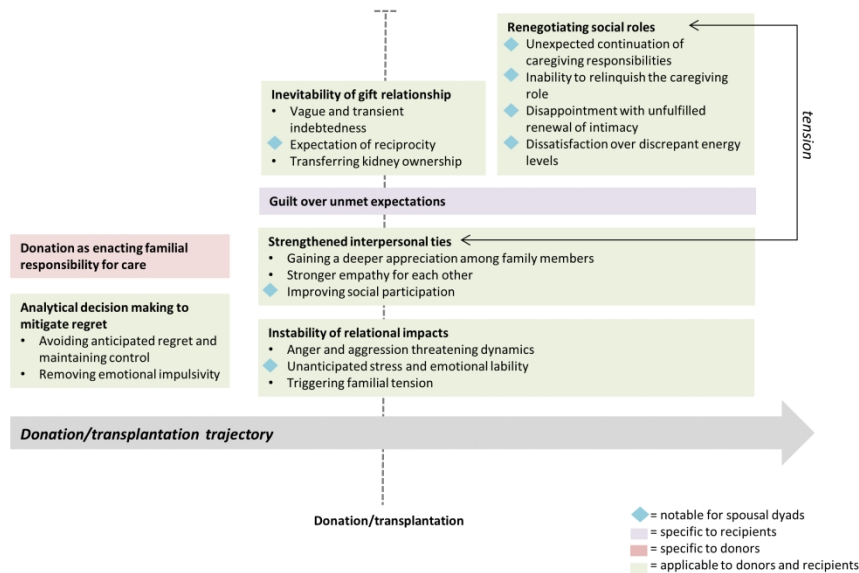
T1: pre-donation/transplantation interview; T2: post-donation/transplantation interview

Figure legends

Figure 1. Thematic schema

Donors and recipients both expected and experienced a strengthened emotional connection and an improved “combined” quality of life. However, at the same time, some dyads were confronted with relationship conflict and tension which were triggered or exacerbated by disappointment with unfulfilled expectations of post-transplantation life, and behavioural and emotional changes. Some donors and recipients were aware of potential relationship strains such as anticipated guilt and indebtedness of the recipient prior to the transplant, however some dyads were still confronted by these challenges of the one-sided “gift relationship” post-donation, which affected their relationship.

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Donors and recipients both expected and experienced a strengthened emotional connection and an improved “combined” quality of life. However, at the same time, some dyads were confronted with relationship conflict and tension which were triggered or exacerbated by disappointment with unfulfilled expectations of post-transplantation life, and behavioural and emotional changes. Some donors and recipients were aware of potential relationship strains such as anticipated guilt and indebtedness of the recipient prior to the transplant, however some dyads were still confronted by these challenges of the one-sided “gift relationship” post-donation, which affected their relationship.

Supplementary Table 1: Interview question guide**1. Time point 1 – Pre-donation: Donors**

- a. Explanation of study, obtain informed consent
- b. How did you meet and could you tell me about your relationship with X?
- c. What are three words that you would use to describe them?
- d. On a scale of 0 (not close at all) to 10 (very close), how would you rate your relationship – why?
- e. What would you say are their strengths (or what you value/respect most about them) and their weaknesses?
- f. How did first come to know that X had kidney disease? How did you come to know that they would need a transplant?
- g. How did you decide to be a donor?
- h. Did someone ask you to donate or did you offer to donate a kidney? Were there other potential donors?
- i. What was the most important motivation to donate a kidney - why?
- j. What reservations or concerns did you have and how did you overcome them?
- k. To what extent do you think your relationship with X influenced your decision – how/why?
- l. How did your relationship with other family members, friends, colleagues have an influence on your decision – how/why?
- m. How do you expect that your relationship with the recipient will change after donation? Can you give an example...?
- n. Is there anything else that you think is important to add?

2. Time point 1 – Pre-donation: Recipients

- a. Explanation of study, obtain informed consent
- b. How did you meet and could you tell me about your relationship with X?
- c. What are three words that you would use to describe them?
- d. On a scale of 0 (not close at all) to 10 (very close), how would you rate your relationship – why?
- e. What would you say are their strengths (or what you value/respect most about them) and their weaknesses?
- f. When did you find out that you had CKD? When did you find out that you needed a transplant? What was your reaction?
- g. Tell me when you were thinking about asking your donor? Were there several potential donors?
- h. What was the most important motivation to accept this kidney from a living donor and not wait for a deceased donor kidney?
- i. How do you expect that your relationship with the donor will change after donation? Can you give an example...?
- j. Is there anything else that you think is important to add?

3. Time point 2 – Post-donation: Donors and recipients

- a. How have you recovered post-surgery?
- b. What kind of thoughts have you had about the transplant?
- c. How much contact have you had with your donor/recipient over the past two weeks? Please expand.
- d. Do you think the transplant is impacting on your relationship in any way – how?
- e. Has the transplant changed the way you view your donor/recipient – how? Can you give an example?
- f. Do you think the transplant has changed the way your donor/recipient views you – how? – Can you give an example?
- g. If yes, how have you been coping with these changes? How do these changes compare with your expectations?
- h. What kinds of things have you discussed with each other about the transplant?
- i. Have you told your donor/recipient about how you have been feeling since the transplant? How did this conversation go?
- j. Did you argue or have any disagreements with your donor/recipient in the past two weeks - why? How was it resolved?
- k. What aspects of a relationship do you believe are most important to cope with the donation/transplant?
- l. Is there anything else that you think is important to add?

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	3
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5
Purpose or research question	#4 Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and	6

1 guiding theory if appropriate; identifying the research
 2 paradigm (e.g. postpositivist, constructivist / interpretivist)
 3 is also recommended; rationale. The rationale should
 4 briefly discuss the justification for choosing that theory,
 5 approach, method or technique rather than other options
 6 available; the assumptions and limitations implicit in
 7 those choices and how those choices influence study
 8 conclusions and transferability. As appropriate the
 9 rationale for several items might be discussed together.
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14	Researcher	#6	Researchers' characteristics that may influence the	6
15	characteristics and		research, including personal attributes, qualifications /	
16	reflexivity		experience, relationship with participants, assumptions	
17			and / or presuppositions; potential or actual interaction	
18			between researchers' characteristics and the research	
19			questions, approach, methods, results and / or	
20			transferability	
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25	Context	#7	Setting / site and salient contextual factors; rationale	6
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28	Sampling strategy	#8	How and why research participants, documents, or	6
29			events were selected; criteria for deciding when no	
30			further sampling was necessary (e.g. sampling	
31			saturation); rationale	
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35	Ethical issues pertaining	#9	Documentation of approval by an appropriate ethics	6
36	to human subjects		review board and participant consent, or explanation for	
37			lack thereof; other confidentiality and data security issues	
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40	Data collection methods	#10	Types of data collected; details of data collection	6
41			procedures including (as appropriate) start and stop	
42			dates of data collection and analysis, iterative process,	
43			triangulation of sources / methods, and modification of	
44			procedures in response to evolving study findings;	
45			rationale	
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50	Data collection	#11	Description of instruments (e.g. interview guides,	See
51	instruments and		questionnaires) and devices (e.g. audio recorders) used	note 1
52	technologies		for data collection; if / how the instruments(s) changed	
53			over the course of the study	
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57	Units of study	#12	Number and relevant characteristics of participants,	7 (and
58			documents, or events included in the study; level of	T1)
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participation (could be reported in results)

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3	Data processing	#13	6-7
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9	Data analysis	#14	6-7
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16	Techniques to enhance	#15	6-7
17	trustworthiness		
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21	Syntheses and	#16	See
22	interpretation		note 2
23			
24			
25			
26	Links to empirical data	#17	Table 3
27			
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30	Intergration with prior	#18	13
31	work, implications,		
32	transferability and		
33	contribution(s) to the field		
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40	Limitations	#19	15
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42	Conflicts of interest	#20	2
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48	Funding	#21	2
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Author notes

1. 6 and (Supp. T1)
2. 8-12 (and Fig 1)

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2 American Medical Colleges. This checklist was completed on 12. September 2018 using
3 <http://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)
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