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Original Investigation

Donor and Recipient Views on Their Relationship in Living Kidney Donation: Thematic Synthesis of Qualitative Studies

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Background: Many donors and recipients report an improved relationship after transplantation; however, tension, neglect, guilt, and proprietorial concern over the recipient can impede donor and recipient well-being and outcomes. We aimed to describe donor and recipient expectations and experiences of their relationship in the context of living kidney donation.

Study Design: Thematic synthesis of qualitative studies.

Setting & Population: Living kidney donors and recipients.

Search Strategy & Sources: Electronic databases were searched to October 2015.

Analytical Approach: Thematic synthesis.

Results: From 40 studies involving 1,440 participants (889 donors and 551 recipients) from 13 countries, we identified 6 themes. "Burden of obligation" described the recipient's perpetual sense of duty to demonstrate gratitude to the donor. "Earning acceptance" was the expectation that donation would restore relationships. "Developing a unique connection" reflected the inexplicable bond that donor-recipient dyads developed postdonation. "Desiring attention" was expressed by donors who wanted recognition for the act of donation and were envious and resentful of the attention the recipient received. "Retaining kidney ownership" reflected the donor's inclination to ensure that the recipient protected "their" kidney. "Enhancing social participation" encompassed relieving both the caregiver from the constraints of dialysis and the recipient from increased involvement and contribution in family life.

Limitations: Non-English articles were excluded.

Conclusions: Living kidney donation can strengthen donor-recipient relationships but may trigger or exacerbate unresolved angst, tension, jealousy, and resentment. Facilitating access to pre- and posttransplantation psychological support that addresses potential relationship changes may help donors and recipients better adjust to changes in the relationship dynamics, which in turn may contribute to improved psychosocial and transplantation outcomes following living kidney donation.

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INDEX WORDS: Living kidney donation; kidney donor; kidney transplant recipient; psychosocial issues; donor-recipient relationship; qualitative research; relationship processes; interpersonal relationships; emotional outcomes; thematic synthesis.

Critical shortages in deceased organ donation have necessitated widespread acceptance of living kidney donor transplantation, which offers optimal health outcomes for most patients with end-stage kidney disease.[1,2] Approximately 35% to 50% of all kidney transplants in high-income countries are from living donors, of whom the majority are parents, spouses, or siblings.[3-7] Among lower-income countries, living donation rates vary widely from 26% of transplants in Panama to 100% in Vietnam, India, and Nepal.[8] Although the quality of life of most donors and recipients is comparable to that of the general population,[9-12] donors and recipients must renegotiate their identity, responsibilities, and relationships. Both donors and recipients have reported relationship tension[13-15] and guilt,[13,16] with donors additionally reporting experiencing neglect[13,17-19] and proprietal concern over the recipient,[17-19] all of which can

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be detrimental to psychological and interpersonal adjustment after transplantation.

The donor-recipient relationship is a key component of living kidney donation. International guidelines universally recommend assessment of the donor-recipient relationship prior to living kidney donation to ensure genuine motivation and realistic expectations.[20-24] However, research on this topic is limited and mostly focuses on the donor's perspective after donation.[25-27] Although many donor-recipient dyads experience increased closeness,[28,29] others have reported relationship deterioration and conflict,[13,14,30] including overprotectiveness,[17] feelings of betrayal,[16] and indebtedness,[13] which they attribute to living kidney donation.[13,15,17]

This study aims to describe expectations and the impact of living kidney donation on the donor-recipient relationship, which may inform communication and support strategies that address donor-recipient relationships in the clinical assessment and follow-up of living kidney donors and their recipients. Our findings and these strategies may ultimately improve psychosocial outcomes for both donors and recipients, as well as their overall satisfaction with the process of donation.

METHODS

We followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ)[31] framework.

Data Sources and Searches

Searches were conducted in MEDLINE, Embase, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO from inception to October 7, 2015. We also conducted searches in Google Scholar, PubMed, ProQuest Dissertation and Thesis, British Library e-Theses Online Service (EThOS), and the Europe E-theses Portal for Doctoral Dissertations, as well as searching reference lists of relevant articles and reviews (Table S1, available as online supplementary material). One author (A.F.R.) screened titles and abstracts and excluded those that did not meet inclusion criteria. Full texts of potentially relevant studies were obtained and assessed for eligibility (Fig 1).

Study Selection

Qualitative studies that examined the expectations and/or experiences of living kidney donation on donor-recipient relationships were included. Studies that involved recipients (all patients with chronic kidney disease stages 1-5, on dialysis therapy, or living donor transplant recipients) and/or donors (related potential or actual donors [siblings and parents] and emotionally related donors [spouses, parents-in-law, and friends]) were eligible. Potential donors involved individuals currently undergoing donor assessment. We excluded articles if they used structured surveys or were quantitative epidemiologic studies, editorials, or reviews. Non-English articles were excluded due to a lack of resources for translation and limited feasibility in understanding and synthesizing cultural and linguistic nuances, and to avoid potential misinterpretation of the author's study. Two authors (A.T. and C.S.H.) cross-checked references against inclusion criteria to ensure that all eligible articles were included.

Data Extraction and Quality Assessment

For each study, we assessed the transparency of reporting because this can provide contextual details for the reader to

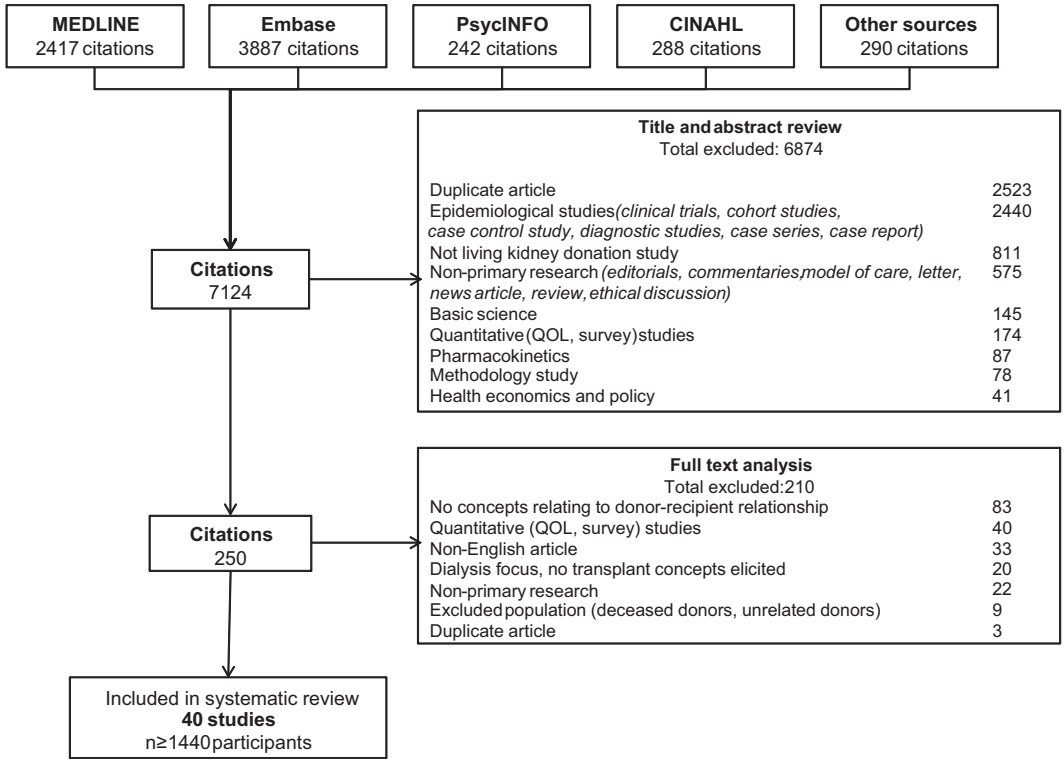

Figure 1. Search results. Abbreviation: QOL, quality of life.

evaluate the credibility, dependability, and transferability of the study findings to their own setting. We adapted the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) framework, which included criteria relating to the research team, study methods, context of the study, analysis, and interpretations.[32] Authors A.F.R. and C.S.H. independently assessed each study and met to resolve any differences.

Synthesis

We extracted all text in results/findings and conclusion/discussions sections of all articles.[31,33] These were entered verbatim into HyperRESEARCH (ResearchWare, Inc, version 3.0.3; 2009) software for coding textual data. To allow interpretation of data in its context and generation of analytical higher order themes, A.F.R. performed line-by-line coding of the findings of the primary studies and identified preliminary concepts inductively by coding text that focused on the relationships between the donor and recipient in living kidney donation. Similar concepts were grouped into themes. Two authors (A.T. and C.S.H.) also read the articles to ensure that the range and depth of data were reflected in the final analysis (investigator triangulation). We identified relationships between themes and developed a conceptual framework.

RESULTS

Literature Search and Study Characteristics

We included 40 studies, of which 4 were PhD dissertations; these comprised at least 1,440 participants (889 donors and 551 recipients; 1 study did not report the number of participants but it was clear that at least 5 donors participated). The type of donor relationship included parent-child (18 studies), sibling (18 studies), spousal (14 studies), and child-parent (7 studies). Fifteen studies included emotionally related and other family members (nephews, siblings-in-law, grandparents, uncles, aunts, parents-in-law, and cousins). The studies were conducted across 13 countries, and 21 (53%) were conducted in an English-speaking country. The studies used focus groups, in-depth semistructured interviews, or open-ended questionnaires to collect data (Table 1).

Comprehensiveness of Reporting

Comprehensiveness of reporting was variable, with studies reporting 5 to 22 of the 27 possible items included in the COREQ framework (Table 2). Thirty studies reported the participant selection strategy. Only 7 studies specified whether theoretical saturation was reached.

Synthesis

We identified 6 themes relating to the donor-recipient relationship: burden of obligation, earning acceptance, developing a unique connection, desiring attention, retaining kidney ownership, and enhancing social participation. The themes are described in the following paragraphs, with selected illustrative quotations provided in Table 3. For each theme, we describe recipients' and donors' expectations prior to transplantation, followed by recipients' and donors' perspectives on their relationship after living kidney donor transplantation.

Themes

Burden of Obligation

Prior to transplantation, some recipients anticipated that they would feel indebted to their donor and expressed concern about how this would affect their relationship with their donor. Some recipients feared that their donor may ask them for a favor in return.

Many donors considered that donating their kidney to their loved one was the "normal" thing to do and did not expect any form of repayment or gratitude. This was particularly true of parental donors, who believed that they were just looking after their children. Some donors were concerned that there was potential for a power-imbalance in the relationship following donation, that is, that the recipient may feel that he or she owes the donor; however, many donors wished for the relationship to remain the same.

Some recipients felt a strong sense of duty to repay the donor and believed that "words alone wouldn't be enough" to give in return for the generous gift. Some recipients believed that they would be "eternally in debt" and the balance of power in their relationship could not return to normal, which resulted in resentment, frustration, and conflict. Adolescent recipients who received a kidney from their parent feared that they could be potentially controlled or pressured with obligations by their donor parent. Other recipients felt obliged to foster a closer connection with their donor despite wanting to minimize their contact with the donor after the donation due to the donor not being "their type"[15] (ie, not the type of person with whom they enjoyed associating). Some recipients felt that having a close relationship and frequent communication with the donor, both before and after the transplantation, served as a constant reminder of the "debt" and made it difficult for the relationship to return to "normal" after the surgery. Some sibling participants were also reminded of their "debt" by their parents.

Earning Acceptance

Some donors, in particular sibling donors, perceived kidney donation as an opportunity to gain approval from the recipient or to earn forgiveness for their past wrongdoings in the eyes of the recipient and their family. One sibling donor donated in the hope that the donation would help "cancel past misdeeds and improve her standing in the family."[13]

Whereas some donors felt their relationship with the recipient improved postdonation, others were disappointed that they were not accepted and appreciated by the recipient after their generous act.

Table 1. Characteristics of Included Studies

Study (Country)	N	Age Range, y	Sex, M:F			Donor Relationship	Timeframe		Data Collection	Conceptual Methodological Framework	Analysis	Topic
			Total	D	R		Pre-Tx	Post-Tx				
Africa												
Schlebusch 1989[52] (ZA)	10 R	—	9:1		9:1	Siblings	—	✓	Open-ended questionnaire	NS or unclear	NS or unclear	Psychological adjustment
Asia												
Joshi 2013[53] (IN)	30 D, 30 R	26-77	34:26	13:17	21:9	NS or unclear	✓	<5 y	Interview	NS or unclear	NS or unclear	QoL
Yi 2003[54] (KR)	14 D	—	4:10	4:10		Parent, sibling, other[a]	<1 wk	<1 wk	F2F interviews	Grounded Theory	Constant comparative analysis	Decision making
Yeh 2012[55] (TW)	90 D	28-71	34:56	34:56		Parent, sibling, other[a]	✓		F2F semi-structured interview	NS or unclear	NS or unclear	Decision making, family involvement
Europe												
Heck 2004[56] (DE)	25 D, 28 R	19-71	—	—	—	Parent, child, spouse, sibling, other[a]		16-24 mo	Semi-structured interview	NS or unclear	Content	Family relationships, psychosocial well-being, support
Schweitzer 2003[57,b] (DE)	67 D, 67 R	—	61:73	21:46	40:21	NS or unclear	✓	✓	F2F interview	NS or unclear	Content	Psychosocial concerns & decision-making
Schweitzer 2004[37,b] (DE)	67 D, 67 R	16-74	61:73	21:46	40:21	NS or unclear	✓	✓	F2F interview	NS or unclear	Content	Evaluation of donors
Langenbach 2009[58] (DE)	11 D		4:7	4:7		Parent, child, spouse, sibling, other[a]	—	1.7-3 y	Semistructured interviews	Grounded theory	Content	Psychological difficulties
Alnaes 2012[59] (NO)	18 D, 18 R	>18	—	—	—	Parent, child, spouse, sibling, other[a]	✓	✓	F2F semi-structured interview	Narrative method	Gift-exchange theory	Psychosocial & sociocultural issues, decision making
Anderson 2005[60] (NO)	12 D	18-60	5:7	5:7				1 wk	F2F semi-structured interview	Phenomenology	Thematic	Donor response
Anderson 2007[61] (NO)	12 D	18-60	7:5	7:5		Parent, child, sibling, other[a]		1 y	Telephone interviews	Phenomenology	Thematic	Physical & psychosocial experiences
Karrfelt 2003[62] (SE)	15 R	9-19	—		—	Parent, other[a]		2-13 y	Semi-structured interviews	NS or unclear	Content	Emotional & psychosocial adaptation

(Continued)

Table 1 (Cont'd). Characteristics of Included Studies

Study (Country)	N	Age Range, y	Sex, M:F			Donor Relationship	Timeframe		Data Collection	Conceptual Methodological Framework	Analysis	Topic
			Total	D	R		Pre-Tx	Post-Tx				
Lennerling 2003[63] (SE)	12 potential D	28-71	6:6	6:6		Parent, spouse, sibling, other,[a] whether children involved NS or unclear	✓		F2F in-depth interview	Phenomenology	Phenomenology	Motivation & decision making
Sanner 2003[64] (SE)	12 R	23-59	7:5		7:5	NS or unclear		1-3 wk to 2 y	F2F interviews	NS or unclear	Content & thematic	Medical concerns, psychosocial issues,
Sanner 2005[45] (SE)	39 D	33-63	16:23	16:23		Parent, spouse, sibling, other[a]	1 d	3 w	Interview	NS or unclear	Narrative structuring	Decision-making & experiences
Schmid-Mohler 2014[65] (CH)	4 R	—	—		—	NS or unclear		✓	F2F interviews	NS or unclear	Content	Self-management post-Tx
Kranenburg 2007[66] (NL)	53 potential D, 91 potential R	18-75	79:65	24:29	55:36	NS or unclear	✓		In-depth interview	NS or unclear	Content	Psychological barriers to LDKT
de Groot 2012[15] (NL)	20 D, 15 R	—	17:18	7:13	10:5	Parent, spouse, sibling, other[a]		0-5 y	Focus groups	I-change model	Content	Expected relationship changes
Schipper 2014[36] (NL)	16 R	27-70	16:14		16:14	NS or unclear		✓	F2F interviews; focus groups	NS or unclear	Content	Expectations & adaptation
Franklin 2003[13] (UK)	20 D, 20 R	—	16:24	8:12	8:12	Parent, sibling		1-5 y	Semistructured interview	Phenomenology	Content	Donor risks, relationships
	30 D, 30 R	—	26:34	13:17	13:17	Parent, sibling		2 d to 25 y	Semistructured interview	Ethnography	Content thematic	Decision to donate, relationships, psychosocial issues
Gill 2009[39,b] (UK)	1 D, 1 R	—	1:1	1	1	Spouse	✓	3-10 mo	Semistructured interviews	NS or unclear	Thematic	Tx failure
Gill 2012[67,b] (UK)	11 D, 11 R	32-63	11:11	5:6	6:5	Parent, spouse, sibling	✓	3 & 10 mo	Semistructured interviews	Hermeneutic Phenomenology	Thematic	Decision making, expected relationship issues, stressors & coping mechanisms
Orr 2007[68,b] (UK)	2 R	—	—		—	NS or unclear		2-8 y	Focus groups	NS or unclear	Thematic & Constant comparative method	Medication adherence

(Continued)

Table 1 (Cont'd). Characteristics of Included Studies

Study (Country)	N	Age Range, y	Sex, M:F			Donor Relationship	Timeframe		Data Collection	Conceptual Methodological Framework	Analysis	Topic
			Total	D	R		Pre-Tx	Post-Tx				
Orr 2007[69,b] (UK)	2 R	—	—		—	NS or unclear		2-8 y	Focus groups	NS or unclear	Thematic	QoL
Sharma1987[35] (UK)	14 D	—	—	—		Parent, sibling		5-10 y	F2F interview	NS or unclear	NS or unclear	Psychological issues
						North America						
Adams-Leander 2011[70] (US)	8 D	>18	2:6	2:6		Parent, child, spouse, other[a]		<1-20 y	F2F interview	Interpretive phenomenological	NS or unclear	African American donors experiences
Debort 1987[38] (US)	5 R	18-50	3:2		3:2	NS or unclear	1 mo	1-3 mo	Semistructured interview	Phenomenology	Thematic	Social support
Duffy 2010[34] (US)	10 D, 10 R	22-48	12:8	7:3	5:5	Sibling		>1 y	F2F interview	Phenomenology	Thematic	Relationships
Fellner 1976[71] (US)	182 D	—	—	—		NS or unclear		✓	Interview & open ended questionnaire	NS or unclear	NS or unclear	Physical & psychological effects
Hauser 1991[72] (US)	39 R	—	21:18		21:18	NS or unclear		16-12 mo	Telephone interview	Strauss & Glaser's chronic illness & QoL framework	NS or unclear	Psychosocial adjustment
Heinemann 2011[73] (US)	5 D, NS or unclear if potential R or R included	—	—	—		Parent, spouse, sibling, other[a]	—	—	Semistructured/ unstructured/life history interviews	Ethnography	Ethnography	Kin relations, caregiving, cultural norms
Hildebrand 2014[18] (US)	21 D, NS or unclear if R included	26-71	23:53	23:53		NS or unclear	—	1-6 y	Focus groups	NS or unclear	Tape-based analysis	Impression management during evaluation
Pradel 2003[74] (US)	3 potential D, 5 potential R, 9 D, 8 R	24-72	11:14	—	—	Parent, child, spouse, sibling, other[a]	—	—	Focus groups	Phenomenology	Content	Medical concerns, communication issues, economic issues about LDKT
Simmelink-Johnson 2004[75] (US)	6 D, 6 R	<40	—	—	—	Spouse		✓	Open-ended questionnaire & interviews	Phenomenology	Phenomenology	LDKT impact on spouse post-Tx
Simmons 1973[76] (US)	80 D, NS or unclear if potential D included	—	—	—		Other[a]	3 d	5 d-1 y	Qualitative interviews; open-response questionnaires	NS or unclear	NS or unclear	Decision making of donors

(Continued)

Table 1 (Cont'd). Characteristics of Included Studies

Study (Country)	N	Age Range, y	Sex, M:F			Donor Relationship	Timeframe		Data Collection	Conceptual Methodological Framework	Analysis	Topic
			Total	D	R		Pre-Tx	Post-Tx				
Waterman 2006[77] (US)	4 D, 26 R	—	—	—	—	NS or unclear	—	✓	Focus groups	NS or unclear	Thematic	Decision making, well-being, psychosocial issues
Oceania												
Tong 2009[78] (AU)	39 potential R, 24 R	20-78	31:32		—	NS or unclear	✓	✓	Focus groups	NS or unclear	Thematic	Psychosocial issues in decision making, recipient refusal, concerns for donor
Williams 2009[19] (AU)	18 D	26-64	—	—		NS or unclear		<11 y	Interviews	Grounded Theory	Constant comparative analysis	Long-term physical & mental experiences
Martin 2014[79] (NZ)	17 potential R	—	8:9		8:9	NS or unclear	✓		Semistructured interviews	NS or unclear	Thematic	Decision making & concerns
Shaw 2015[80] (NZ)	21 D, NS or unclear if R included	—	—	—		Spouse, whether parent, child, silbing, or other[a] involved NS or unclear	—	✓	In-depth interview	Phenomenology	Phenomenology	"Gift" relationship

Abbreviations: —, not stated, unclear, or unable to ascertain; ✓, study met criteria; Blank boxes, the criteria not applicable in this study; AU, Australia; CH, Switzerland; D, donor; DE, Germany; F2F, face-to-face; IN, India; KR, Republic of Korea; LDKT, living donor kidney transplantation; NL, the Netherlands; NO, Norway; NS, not stated; NZ, New Zealand; QoL, quality of life; R, recipient; SE, Sweden; TW, Taiwan, Tx, transplant(ation); UK, United Kingdom; US, United States; ZA, South Africa.

Definitions: constant comparative method, the simultaneous collection of data and abstraction into categories, as comparisons between concepts and themes are made and the data are grouped according to relationship patterns; content analysis, a deductive approach whereby concepts and theories are identified before searching for their occurrence in the data; ethnography, to describe and understand individual social and cultural groups; gift-exchange theory, gift exchange is cycle bound by key obligations: to give, to receive and to reciprocate or repay and is influenced by various factors, including obligation, duty, respect, and self-interest; grounded theory, develop theories about social phenomena that are built up inductively through analysis and comparisons in the empirical data; hermeneutics, to examine the way people develop interpretations of their life in relation to their previous life experiences; interpretative analysis, detailed examination of an individual's personal account; I-change model, predisposing social factors determine a person's awareness, attitudes, susceptibility to social influences, and self-efficacy regarding a certain behavior, which in turn affects a person's intention and motivation to carry out this behavior; narrative methodology, focuses on the structure and nature of a person's oral first person narratives in order to understand their interpretation of the world; phenomenology, explores individuals' subjective experiences by focusing on individuals' own perceptions, understanding, and interpretations; thematic analysis, an inductive approach whereby concepts and theories are derived from the data.

[a]Other consisted of nephews, siblings-in-laws, friends, grandparents, uncles, aunts, parents-in-law, "emotionally related," and cousins.

[b]Studies used the same sample as the respective study by the same author.

Table 2. Comprehensiveness of Reporting in the Included Studies

Item	Reference Number of Study	No. of Studies
Research team		
Interviewer/facilitator identified	13, 15, 18, 34-36, 38, 45, 54, 59, 62, 63, 65, 67-70, 73, 80	19
Credentials	13, 18, 38, 65, 67, 70, 73, 75, 80	9
Occupation	13, 35, 37, 57, 62, 63, 67-70, 73, 77	12
Sex	13, 15, 34-36, 38, 45, 59, 62-65, 67-70, 73, 75, 80	19
Experience/training in qualitative research	35, 65, 69, 77	4
Established relationships prior to study	34, 45, 64, 67	4
Participant selection		
Selection strategy (eg, purposive)	15, 18, 19, 34, 36-38, 45, 53, 54, 59, 60, 62-70, 72-79	29
Method of approach	15, 18, 19, 34, 36, 54, 58, 59, 62-70, 73-75, 77-79	23
Sample size	13, 15, 19, 34-38, 45, 53-55, 57-80	36
Number/reasons for nonparticipation	15, 18, 34, 35, 45, 58, 62-66, 68-70, 72-74, 76, 78, 79	20
Setting		
Venue of data collection	15, 34, 36-38, 45, 57, 59, 60, 62-64, 66, 67, 72, 74, 77, 78, 80	19
Presence of nonparticipants	13, 15, 34, 37, 54, 57, 59, 60, 62, 66, 67, 77, 78	13
Description of the sample	13, 15, 18, 19, 34-38, 45, 53-70, 72-75, 77-79	35
Data collection		
Questions or topic guide	13, 15, 18, 34-38, 55-57, 60-63, 65, 66, 69, 70, 72-75, 77-80	27
Longitudinal (follow-up) interviews/focus groups	15, 18, 34, 36, 38, 39, 45, 54-57, 59-62, 64-70, 72-74, 76, 78, 79	28
Audiovisual recording	15, 18, 19, 34, 36-39, 45, 54, 57-61, 63, 65, 67-70, 73, 75, 77-79	26
Field notes	15, 36, 60, 68-70, 73, 78	8
Duration	13, 15, 36, 37, 39, 54, 55, 61-64, 67-69, 75, 77, 80	17
Theoretical saturation	15, 36, 54, 60, 65, 79	6
Transcripts returned to participants	59, 68-70, 80	5
Data analysis		
Researcher triangulation	13, 15, 18, 36, 45, 57, 62-65, 67-70, 72, 74-78, 80	21
Derivation of themes	13, 15, 18, 19, 34, 36, 38, 45, 54, 56-58, 60, 61, 63-65, 67-70, 73-75, 77-80	28
Process for translation of data	64, 66, 74	3
Data preparation and transcription	15, 18, 19, 34, 36, 45, 54, 58-61, 63, 65-70, 73-75, 77, 78, 80	24
Use of software	15, 19, 34, 36, 54, 65, 68-70, 73, 78, 79	12
Member checking by participants	36, 54, 59, 61, 65, 66, 68-70, 78, 80	11
Reporting		
Quotations	13, 15, 18, 19, 34-36, 38, 45, 54-57, 59-80	35
Range and depth of insight into donor-recipient relationships	13, 15, 34, 36, 38, 54-56, 59, 64, 73, 74, 77	13

Developing a Unique Connection

Participants sometimes expected that living kidney donation would result in a strengthened relationship marked by increased closeness, support, and higher frequency of contact between them and their recipient/donor. For many donors and recipients, these expectations were met and they described an inexplicably unbreakable bond with the respective donor/recipient postdonation. They believed that the transfer of such a "special kind of gift" brought them closer together, either reawakening dormant affections or further strengthening their connection, in a way that those external to the relationship may not comprehend.

Desiring Attention

Some recipients suspected that donation was an act of manipulation from their sibling in order to be treated as the "hero" and increase their already favored status within the family.

Both donors and recipients expressed feelings of jealousy and rivalry because their family and hospital staff had to focus their attention and care on the donor and recipient postdonation. Some donors felt angry, exploited, and abandoned when they perceived that medical attention was shifted back to the recipient after transplantation because the focus was on avoiding rejection of the kidney. One donor described feeling "very much like a spare part and not like a real patient."[34] Sibling donors perceived that their recipient had been doted on and given preferential treatment due to their illness, and they believed that donation was a way for them (the donors) to "become the martyr and take center stage"[13] away from their sibling. Donors who felt they were "treated differently" from their

Table 3. Illustrative Quotations

Theme	Participants Quotations (Italicized) and/or Authors' Explanations	Contributing References
Burden of obligation	"*After the transplant it was really difficult to [argue] with her [the donor], very hard to say no to her. The relationship wasn't normal, we were equals before and then suddenly I owed her something…I built up this resentment.*" (Recipient[13]) *"I just know that it means they're kind of connected to me now, and I don't want that, physically I would want them, … but just the whole shebang afterwards…I just know they'll hold me to ransom and but at that point there'd be nothing I could do."* (Potential recipient[79]) *"I have the feeling I have to be grateful all my life"* (Recipient[15]) *"In many ways I would have liked to have refused but that would have caused so much conflict, and I needed their (family) support. I knew what it would be like afterwards, eternal gratitude. I mean even if you borrow his car he expects you to be thankful for evermore, and I was so right. He never lets me forget, and I always feel like the child who has to be obedient as if I can never be grateful enough."* (Recipient[13])	13, 15, 34, 36, 38, 45, 52, 54, 56, 57, 60, 64-69, 74, 77, 78
Earning acceptance	*"I was always the rebel, and Mary [the recipient] was the goodie goodie. Our parents had banished me, but all was forgiven once I offered to be a donor."* (Donor[13]) *"I am in the middle of a longstanding major rupture with my family. Things have improved only very little after my sister's transplantation."* (Donor[59]) *"I was really hoping I would be chosen [as the donor]. Here was my chance to do something for my family to be more of a part of it. I was just envious because I wanted it to be me."* (Potential donor[34]) One sibling donated to pay back the recipient for care received during her childhood, and one sibling donated in the hope that donation would help to cancel past misdeeds and improve her standing in the family.[13] *"The reason I am going to give my kidney to my sister is because I was the most trouble-making one among my six siblings. I was such a bad student at school, fighting with friends and hanging around outside."* (Donor[54])	13, 15, 34, 54, 57, 59
Developing a unique connection	"*It's like a secret connection that no one can understand or ever break.*" (Recipient[34]) *"There has been a closer relationship between us as if we were connected at a different level. We are definitely more sympathetic to each other's needs… The feeling is of a true bond above and beyond what we had prior to the transplant."* (Recipient[75])	13, 15, 34, 38, 45, 53, 56, 57, 59-62, 64, 65, 67, 74, 75
Desiring attention	*"I felt neglected after the operation was over. My brother got all the publicity and I was left on my own. I hated him, I wished he was dead."* (Donor[35]) Note: This donor did not speak to his brother for a period of 4 years. "*I felt very much like a spare part…and not like a real patient*" (Donor[34]) *"She [my sister] was always special, and she always managed to spoil my birthdays by getting sick. I was really quite jealous and sometimes wished that I could have dialysis."* (Donor[13]) *"The [recipient] is the number one thing. And this is how it has always been and it only got worse once they had the transplant. They really can do no wrong anymore."* (Donor[34])	13, 34, 35, 45, 58, 70, 78
Retaining kidney ownership	*"It's strained our relationship… he makes me feel responsible for his kidney. He'll ask me 'how is your output,' or 'maybe you should call the doctor,' or 'don't you think you should go lay down.'"* (Recipient[38]) *"It's hard being a donor and a carer and a mother… it's really hard when you see your daughter abusing it."* (Donor[19]) *"I guess you say it's my kidney, but then you think: no, maybe that's wrong."* (Recipient[62]) "*I secretly feared that my husband might start smoking again and waste the kidney. But I was not going to tell the treatment team that.*" (Donor[18]) *"Things have not gone that well for my husband (recipient) even though the transplant was initially successful. The reason why is my husband has continued to smoke…This is a hard issue for me."* (Donor[18])	13, 15, 18, 19, 34, 38, 53, 62

(Continued)

Table 3 (Cont'd). Illustrative Quotations

Theme	Participants Quotations (Italicized) and/or Authors' Explanations	Contributing References
Enhancing social participation	*"We've started a new life, and we're really enjoying life. And it's made us do things, like buy a motor home…because life is so short and…it can be taken from you anytime. Do what you want to do now, and we're doing it, and we're loving it"* (Donor[19]) "*I tend to hide it if I'm not feeling well. I'll get up at four o'clock in the morning, and sit up after they've all gone to bed, just so he [the donor] won't know if I don't feel good.*" (Recipient[38]) *"I don't give up, you shouldn't complain, you don't want to be unthankful*" (Recipient[36]) *"My husband also said: I expected you to be able to do more things. This led to tension in our relationship."* (Recipient[36]) "*Now he [the recipient] is a much more open and social person. He focuses a lot more on me as a person, asking me how I am and if things are going well."* (Donor[61]) Roles in the relationship have changed entirely: the recipient complains, is inactive and unsatisfied; the donor is striving to encourage and support the recipient, takes over his responsibilities or resorts to new activities on her own. The relationship balance, which was asymmetrical even before the transplantation, has shifted to a totally different direction. The new situation is very difficult for both partners.[56]	19, 36-38, 54, 56-58, 61, 63, 65, 70, 72, 74

sibling expressed feelings of resentment and believed that the relationship became more distant following donation. One donor expressed that he felt neglected after the operation and did not speak to his brother for 4 years because his brother "got all the publicity" and he was "left on [his] own."[35]

Retaining Kidney Ownership

Some recipients perceived donors as "meddlesome" and reported that donors had involved themselves in the longer term maintenance and care of "their" kidney by checking whether the recipient was following their medication regimen, requesting medical information on the current functioning of the kidney, and offering lifestyle advice. Some recipients believed their relationship with the donor was strained due to the donor reportedly pressuring them to care for the transplanted kidney. Other recipients reported feeling internally conflicted between their desire to please the donor, to whom they felt indebted, and their need to act independently. Some donors felt frustrated when they believed the recipient was not taking care of "their" organ, found it difficult to "let go" of their ownership of the kidney, and were concerned that "if it [the kidney] fails, I'll feel like a part of me has failed."

Enhancing Social Participation

Many participants, particularly spousal donors, believed that living donor kidney transplantation would result in an improved quality of life for both the recipient and donor through increased participation by the recipient in family life. Some participants expected a "rebirth of their loved one [recipient]" and that "everything will change for the better." Some participants also expected transplantation to improve psychological outcomes, in particular depressive and anxious symptoms. Some recipients perceived pressure to meet the "high" expectations of the donor to be able to "do more things"[36] and chose to conceal their true feelings and physical limitations to avoid disappointing their donor and did not want to appear ungrateful. For example, some donors did not reveal feeling undersupported by those around them and the difficulty they were having letting go of their long-established feelings of dependency.[37] Another donor described hiding their physical symptoms, stating "I'll get up at 4 o'clock in the morning, and sit up after they've all gone to bed, just so he [the donor] won't know if I don't feel good."[38]

Donors experienced frustration when the recipient complained about experiencing adverse effects of medication, which lead to arguments and relationship tension.

When medical complications such as transplant failure occurred, both spousal and child recipients expressed that this sometimes instigated relationship strain. Donors expected to be relieved of their caregiving role and became disappointed when their recipient's health did not improve. One donor described that his wife's kidney failed after the surgery and his prior caregiving role increased after transplantation: he had to care for her emotionally because she had severe depression and anxiety and was talking about taking her own life when she was discharged from the hospital.[39]

DISCUSSION

The donor-recipient relationship prior to living kidney donation is an integral component of donor

assessment to ensure that the decision to donate is free of coercion, but it may be neglected following transplantation in routine clinical care. We found that many donors and recipients both expected and experienced increased closeness and improvement in the quality of their relationship, marked by higher frequency of contact, greater perceived emotional support, and a strengthened and unique emotional connection with the respective donor or recipient. However, other donor-recipient pairs experienced relationship conflict and tension characterized by feelings of jealousy, anger, rivalry, abandonment, disappointment, and guilt.

Overall, in donor-recipient pairs that encountered difficulties in their relationship, the donors' and/or recipients' experiences of posttransplantation life appear to be misaligned with the expectations held prior to transplantation. For example, some donors and/or recipients were disappointed that transplantation had not led to the desired level of physical and emotional participation in family life and improvements in anxiety and mood. Additionally, donors were frustrated when they did not receive the desired amount of attention, recognition, and approval or when relationships failed to be restored with the recipient, family, and friends. Some donors and/or recipients found it difficult to renegotiate the balance of dynamics after the asymmetrical gift-exchange that is living donor transplantation. Some donors struggled with proprietorial concern over "their" kidney and recipients felt a perpetual sense of duty to demonstrate gratitude to the donor. Overall, interpersonal complications were intensified in pairs that appeared to have pre-existing relationship stress.

We found notable differences in expectations and experiences of donors and recipients according to the type of their relationship. Biologically related (eg, parent donors and sibling donors) and emotionally related (eg, spousal donors) donor-recipient pairs regarded their posttransplantation bond as strengthened. In both child and adult sibling pairs, interpersonal strains between the donor and recipient were amplified by other relationships in the wider family context. For example, when sibling-donors felt "forgotten" after transplantation or their position within the family hierarchy was not elevated, they not only felt let down by the recipient, but also by their respective parents and siblings. Moreover, while the recipient's obligation to be grateful to the donor-sibling was often self-imposed, it was also perceived to be reinforced by the behavior of their parents (eg, their parents consistently thanking their donor sibling and reminding the recipient of how their donor sibling has helped them).

The expectations and motivations of the donor appear to have an integral role in maintaining a well-functioning donor-recipient relationship. Although motivations of donors are well-documented in the literature,[17] namely to improve the health of the recipient, our review details a range of motivations that relate to their expectations regarding the relationship posttransplantation, including gaining attention from relatives, restoring family connections, and improving the recipient's participation in family life. Unrealistic and unmet expectations can cause donors to feel "disappointed" and "used," which can contribute to poor relationship outcomes and overall dissatisfaction with transplantation. Spousal donor-recipient pairs hoped that transplantation would relieve the donor of social caregiving burdens and enable the recipient to participate and contribute in family life. Medical complications, such as transplant loss, can lead to serious disappointment and further encumber the relationship. This highlights the need to comprehensively assess the donor's expectations of the outcomes of transplantation and counsel donors to better prepare them for the possible outcomes. The recent KDIGO (Kidney Disease: Improving Global Outcomes) guideline recommends that the donor's expectations of the outcomes of donation, including impacts on their future relationship with the recipient, are reviewed with the donor during a formal psychosocial evaluation without the recipient present.[40] However, such guidelines are not supported by links to specific resources or conversational guides to facilitate clinicians in their implementation.

The paradigm of the "gift relationship" and "gift of life" are used widely in the context of organ transplantation,[41,42] for which gifts are in theory given voluntarily, but in actuality, they are given and recompensed under obligation.[43] Our review highlights that this "tyranny of the gift"[44] is evident in live kidney transplantation because some recipients felt bound to the donor and had difficulty rebalancing their relationship dynamic posttransplantation. This was marked for pairs with closer relationships, such as spousal pairs and siblings with frequent contact, for whom the closeness of the relationship functioned as a constant reminder of their "debt."

Our review was conducted using a comprehensive search of the literature followed by an independent assessment of study reporting by multiple authors using a standard framework.[32] Data were coded using software that allows an auditable development of themes. Although previous quantitative and qualitative studies have identified changes in the donor-recipient relationship, we created a novel conceptual framework to provide insight into process underlying such changes across a broad range of participants and experiences, as shown in Fig 2. However, our study has some potential limitations. Although our review includes studies from a range of countries,

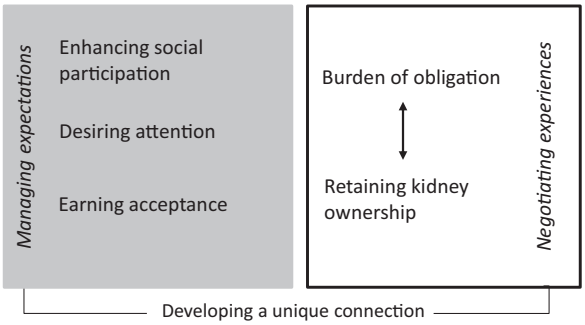

Figure 2. Thematic schema.

non-English articles were excluded due to a lack of resources for translation. Thus, the transferability of findings to other settings may be limited. As is standard practice in thematic synthesis, our review analyzed data reported in the primary studies and we did not attempt to access the original transcripts and field notes.

We suggest that in the screening and workup for living donor kidney transplantation, health professionals explore the range of potential donor motivations, including the expected gains as identified in the study, and explicitly address the expectations of donors and recipients. Such conversations may help ensure that their hopes are realistic and achievable through transplantation and ensure that both donors and recipients can be better prepared to deal with potential disappointment, should it arise. If difficulties in the relationship or potentially unrealistic expectations are identified through such conversations, donors and recipients should be counseled prior to donation. Psychological services, such as cognitive behavioral therapy, can target the dysfunctional thoughts and beliefs of donors and recipients so that they can be challenged and refuted. We also suggest that donors and recipients may be interviewed together as part of the psychosocial assessment, enabling the health professional to observe and gain an understanding of their interpersonal dynamic. The KDIGO donor assessment guidelines recommend that unrealistic expectations of donation should not necessarily preclude a donor from donating (unless such expectations remain despite counseling), but may be an indication of the need for additional support or therapeutic interventions for optimal outcomes.[40] Furthermore, it is evident that the donor-recipient relationship is affected by their greater family dynamics, especially in sibling pairs. Thus, including additional family members in the donor assessment process may assist clinicians in establishing whether the donor's decision is free from family pressure and assess the potential donor's ability to recover.

After transplantation, we suggest that the transplantation team give explicit attention to donors.[45] This may not only help maintain the functioning of the relationship, but also improve the donor's overall satisfaction with donation. Additionally, facilitating access to psychological services in which professionals have knowledge and experience in live donation is recommended for donor-recipient pairs that are having difficulty negotiating the altered dynamics of their relationship postdonation. Spousal donors may particularly benefit from such services, which have been shown to improve the perceived closeness of couples and reduce their distress in other health contexts, such as cancer.[46-48]

Despite calls for research to focus on the donor-recipient dyad,[17,25,27] our review has identified that although many studies address the donor-recipient relationship among broad psychosocial outcomes, there is a paucity of studies that have directly examined in detail the impact of living kidney donation on the relationship between the donor and recipient. Furthermore, to our knowledge, no study has examined the donor-recipient relationship from the perspective of both the donor and the recipient (ie, both parties involved in the relationship), with the majority of studies being conducted from the donor's perspective[25-27] and conducted postdonation. Whereas many current donor guidelines specifically address this issue of posttransplantation expectations and the donor-recipient relationship,[20-24] recipient guidelines do not address this explicitly.[49-51]

Living kidney donation can strengthen the connection between donor-recipient pairs, but can also elicit unresolved or additional relationship conflict resulting from feelings of anger, tension, resentment, and disappointment. Ensuring that donors and recipients have realistic expectations and a sound understanding of life posttransplantation, as well as access to psychological services to facilitate adjustments in relationship dynamics, is a key component in engendering a well-functioning donor-recipient relationship. Ultimately, these efforts can contribute to overall improved satisfaction, well-being, and outcomes in living kidney donor transplantation.

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SUPPLEMENTARY MATERIAL

Table S1: Search strategies.

Note: The supplementary material accompanying this article (http://dx.doi.org/10.1053/j.ajkd.2016.09.017) is available at www.ajkd.org

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