The Motivations and Experiences of Living Kidney Donors: A Thematic Synthesis

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Background: Living kidney donation is associated with better recipient outcomes compared with deceased kidney donation, but living kidney donors face the risk of physical and psychological complications. The aim of this study was to synthesize published qualitative studies of the experiences and perspectives of living kidney donors.

Methods: We conducted a systematic review and thematic synthesis of qualitative studies of motivations to donate and experiences after donation of living kidney donors. MEDLINE, Embase, PsycINFO, CINAHL, and reference lists of articles were searched to April 2011.

Results: 26 studies involving 478 donors were included. We identified 6 themes about the decision to donate: compelled altruism, inherent responsibility, accepting risks, family expectation, personal benefit, and spiritual confirmation. Three themes dominated the impact of donation and postdonation: renegotiating identity (including subthemes of fear and vulnerability, sense of loss, depression and guilt, new appreciation of life, and personal growth and self-worth), renegotiating roles (including subthemes of multiplicity of roles, unable to resume previous activities, and hero status), and renegotiating relationships (including subthemes of neglect, proprietorial concern, strengthened family and recipient bonds, and avoidance of recipient indebtedness).

Conclusions: Kidney donation has a profound and multifaceted impact on the lives of donors and requires them to renegotiate their identity, roles, and relationships. Strategies to safeguard against unwarranted coercion, and to maximize donor resilience, capacity to negotiate their multiple roles as a patient and carer, emotional fortitude, and ability to have balanced expectations and relationships with the recipient and the family are needed to ultimately protect the safety and well-being of living kidney donors. *Am J Kidney Dis.* 60(1):15-26. © *2012 by the National Kidney Foundation, Inc.*

INDEX WORDS: Kidney donation; kidney transplantation; living donation; qualitative research; systematic review; quality of life.

Editorial, p. 1

D ue to the critical shortage of deceased donor kidneys available for transplant, live kidney donation is becoming increasingly common worldwide. For example, there were an estimated 27,000 registered living donations conducted worldwide in 2006, with most countries citing a 50% increase during the past decade.¹ Living kidney donation represents almost half of all kidney transplants in developed countries such as the United States and United Kingdom.²⁻⁵ Although recipient outcomes are favorable compared with deceased kidney donation, live donors face the risk of death, surgical complications, and potential long-term health and psychological problems.⁶⁻⁹

In the absence of large long-term prospective studies, the medical and psychosocial outcomes for living kidney donors are uncertain.¹⁰ Clinical practice guidelines predominantly focus on monitoring transplant outcomes in recipients and screening of potential living donors.^{5,11-14} Although donor follow-up is advocated, mechanisms to ensure monitoring and follow-up of living kidney donors are lacking. In most countries, screening of live donors has been vital in minimizing the medical and psychosocial risks, yet there still have been reports of donor depression and suicide and reduced quality of life associated with donor-recipient relationship problems, transplant complications, and poor recipient outcomes.^{15,16} Qualitative research can offer rich narrative data to provide an in-depth understanding of donor experiences and perspectives that surveys alone may not capture. Thematic synthesis of qualitative studies offers a highlevel analytical abstraction of findings derived from primary qualitative studies of living kidney donors' perspectives.

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Study	No.	Donor Age (y)	Donor Type	Donation Era	Time Postdonation	Data Collection	Conceptual Methodological Framework	Analysis	Торіс
Study No. Age (Age (y)	Donor Type	LIA	FOSICIONALION	Data Collection	Flainework	Analysis	Торіс	
Andersen et al, ¹⁹ 2005 (NO)	12	18-60	Parent, child, sibling, grandparent, aunt/ uncle	2003	1 wk	Face-to-face semistructured interview	Phenomenology	Thematic	Donor responses 1 wk after donation
Andersen et al, ²⁰ 2007 (NO)	12	18-60	Parent, child, sibling, grandparent, aunt/ uncle	2003	12 mo	Face-to-face semistructured interview	Phenomenology	Thematic	Donors' experiences after transplant failure or success in the recipient
Baines et al, ²¹ 2001 (US)	7	—	Parent	—	3-12 mo	Face-to-face semistructured interview	Explorative	Social network	Family relationships after donation
Brown et al, ²² 2008 (CA)	12	26-65	Spouse, sibling, parent, friend	—	4-29 y	Face-to-face semistructured interview	Phenomenology	Thematic	Decision-making process, effects of giving a kidney
Brown et al, ²³ 2008 (CA)	12	26-65	Spouse, sibling, parent, friend	—	4-29 y	Face-to-face semistructured interview	Phenomenology	Thematic	Experiences with the health care system
Crombie & Franklin, ²⁴ 2006 (UK)	20	_	Parent, sibling	—	—	Semistructured interview	Ethnographic	Thematic	Postoperative anxieties, experiences, and relationships
Fellner & Marshall, ²⁵ 1968 (UK)	12	_	_		5 wk-18 mo	Face-to-face open-ended interview	Phenomenology	_	Life after donation, physical and psychological effects
Frade et al, ²⁶ 2011 (PT)	45	—	Parent, sibling, daughter	2002-2008	12 mo	Open-ended questionnaire	_	_	Perceptions of living kidney donation
Franklin & Crombie, ²⁷ 2003 (UK)	40	40	Parent, sibling	—	1-5 y	Face-to-face semistructured ethnographic interviews	Phenomenology, ethnography	Content	Decision to donate, relationships after donation
Gill & Lowes, ²⁸ 2008 (UK)	11	_	Spouse, sibling, parent	2003-2004	3 & 10 mo	Face-to-face semistructured interviews	Phenomenology	Thematic	Emotional effects after donation
Haljamae et al, ²⁹ 2003 (SE)	10	44-75	Sibling, spouse, parent	1990-1995	_	Face-to-face open-ended interview	Phenomenology	Grounded theory	Impact of recipient transplant loss
Heck et al, ³⁰ 2004 (DE)	31	27-71	Parent, daughter, sibling, spouse, friend	1996-2001	—	Face-to-face semistructured interviews	Case study	Content	Family relationships, psychological well-being, support needs
Kemph et al, ³¹ 1969 (US)	27	15-59	Parent, sibling	—	—	Observation	Case study		Family relationships, attitudes to donors after transplant
Kemph, ³² 1971 (US)	1	15	Sibling	—	—	Observation, Interview	Case study		Effects of giving a kidney and attitudes toward the recipient
Langenbach et al, ³³ 2009 (DE)	11	24-71	Spouse, parent, sibling, friend, son	—	2-3 y	Face-to-face semistructured interviews	—	Grounded theory	Psychological problems

 Table 1. Characteristics of the Included Studies

Study	No.	Donor Age (y)	Donor Type	Donation Era	Time Postdonation	Data Collection	Conceptual Methodological Framework	Analysis	Торіс
Lungsford et al, ³⁴ 2007 (US)	18	30-62	Parent, sibling, spouse, altruistic	1993-2003		Telephone structured interview	Case comparison	Thematic	Racial differences in donation, perception of living with 1 kidney
Marshall & Fellner, ³⁵ 1977 (US)	10	—	Parent, sibling	_	8-9 y	Face-to-face open-ended structured interviews	Phenomenology	_	Experiences of donors after donation
Massey et al, ³⁶ 2010 (NL)	24	33-84	Altruistic	2000-2008	3-97 mo	Face-to-face semistructured interviews	Phenomenology	Thematic	Experiences of donation
Pradel et al, ³⁷ 2003 (US)	9	24-71	Sibling, child, parent, spouse, friend	_	_	Focus groups	Phenomenology, comparison	Thematic	Thoughts of donors over live donor kidney transplant or laparoscopic nephrectomy
Rana & Akoh, ³⁸ 2010 (UK)	56	_	Spouse, sibling, parent, partner, child, altruistic	2003-2008	1-12 wk	Open-ended questionnaire	Phenomenology	_	Perspectives on transplantation
Sanner, ³⁹ 2005 (SE)	39	33-63	Parent, sibling, child, spouse, friend, distant relative	2000	0-3 wk	Face-to-face open-ended interview	Phenomenology	Narrative structuring	Decision-making and postsurgery experiences
Sharma & Enoch, ⁴⁰ 1987 (UK)	14	_	Parent, sibling	1977-1979	5-10 y	Face-to-face open-ended interview	Case comparison	_	Experiences of donors
Walsh, ⁴¹ 2004 (GB ^a)	8	_	Parent, sibling	2000-2001	_	Face-to-face semistructured interviews	Phenomenology	Thematic	Family support, experiences
Williams et al, ⁴² 2007 (AU)	18	26-64	Parent, sibling, spouse, distant relative, friend	_	_	Face-to-face semistructured interviews	Phenomenology	Grounded theory	Experiences with health care system during donation
Williams et al, ⁴³ 2009 (AU)	18	26-64	_	_	0-11 y	Face-to-face formal interviews	Phenomenology	Grounded theory	Long-term physical and mental experiences for living donors
Zeiler et al, ⁴⁴ 2010 (SE)	1	—	Parent	—	_	Face-to-face interview, case study	—	Narrative	Parental donors' decision making experience

Note: Laparoscopic nephrectomies were used in Lungsford et al³⁴ and Pradel et al³⁷; open/laparoscopic nephrectomies were used in Rana and Akoh.³⁸

Abbreviations and definitions: —, not stated; AU, Australia; CA, Canada; content analysis, deductive methodology that involved identification of codes before searching for their occurrence in the data; DE, Germany; ethnography, to discover and describe individual social and cultural groups; GB, Great Britain; grounded theory, theories are grounded in the empirical data and built up inductively through a process of careful analysis and comparisons; narrative analysis, focuses on ways in which people make and use stories to interpret the world; NL, the Netherlands; NO, Norway; phenomenology, to study people's understanding and interpretations of their experiences in their own terms and emphasizing these as explanations for their actions; PT, Portugal; SE, Sweden; social network analysis, encompasses theories, models, and applications that are expressed in terms of relational concepts or processes; thematic analysis, concepts and theories are inductively derived from the data; UK, United Kingdom; US, United States.

^aIn particular, Northern Ireland.

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Experiences of Living Kidney Donors

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This study aims to synthesize published qualitative studies of the experiences and perspectives of living kidney donors. A broader understanding of the perspectives of living kidney donors can inform the development of health care services and policies to protect the safety and well-being of living donors.

METHODS

Data Sources and Searches

MeSH terms and text words for living donation and kidney transplant were combined with MeSH terms and text words for psychological, social, and quality-of-life concepts and qualitative research terms (Table S1, available as online supplemental material). The searches were conducted April 11, 2011, in MEDLINE (1948 to week 5, 2011), PsycINFO (1806 to April week 1, 2011), EMBASE (1980 to week 14, 2011), and CINAHL (1982 to week 5, 2011). We also searched reference lists of relevant articles and Google Scholar and contacted experts in the field for potentially relevant studies. The journals *Qualitative Health Research* and *Qualitative Research* were searched using terms relating to transplantation. We screened titles and abstracts and discarded those that did not meet the inclusion criteria. Full texts of potentially relevant studies were retrieved and examined for eligibility.

Study Selection

Qualitative studies using interviews, focus groups, or observations to explore the motivation and postdonation experiences from the perspective of living kidney donors were included. Studies of deceased organ donation, potential donors, or nonkidney donation were excluded. Commercial donors were excluded because their experiences and motivations are vastly different from those of noncommercial donors and thus are inappropriate to combine in a thematic synthesis. Non-English articles were excluded to prevent linguistic bias in translations. Articles were excluded if they used structured surveys and reported only quantitative data because thematic synthesis is feasible and appropriate for synthesizing only qualitative research findings. Nonprimary research articles such as editorials, reviews, and commentaries were excluded.

Data Extraction and Quality Assessment

We assessed the explicitness and comprehensiveness of reporting of each primary study. This can provide contextual details for readers to assess the trustworthiness and transferability of the study findings to their own setting. We used a framework that was developed for reporting qualitative studies, which included criteria specific to the research team, study methods, context of the study, analysis, and interpretations (Table S2).¹⁷ Two reviewers (A.T. and G.M.) independently assessed each study and resolved any disagreement by discussion.

Data Synthesis and Analysis

To synthesize the findings of the included studies, we used the technique of thematic synthesis described by Thomas and Harden.¹⁸ For each article, we extracted all participant quotations and text under the Results/Findings or Conclusion/Discussion section of the article. These were entered verbatim into HyperRESEARCH (ResearchWare, INC.2009, version 2.8.3, www.researchware. com), software for storing, coding, and searching qualitative data. We performed line-by-line coding of the findings of the primary studies, identified descriptive themes, and then developed analytical themes. For each article, we coded the text and recorded concepts that focused on the postdonation experiences and perspectives of living kidney donors and identified common and divergent

concepts and ideas. Subsequent articles were analyzed similarly, and we translated the concepts from one study to another by adding coded text to existing concepts or created a new concept when necessary. We identified themes inductively without a pre-existing framework. We identified relationships between themes to develop a new analytical framework to extend the findings offered by the primary studies.

RESULTS

Literature Search

Our search yielded 2,491 articles. Twenty-six studies involving 478 living kidney donors were included in the review (Item S1). Study characteristics are listed in Table 1. Participants were either related (parent, child, sibling, spouse, grandparent, or distant relative) or nonrelated donors (friend or altruistic nondirected). The studies were conducted in the United States, United Kingdom, Continental Europe, Canada, and Australia. Across all studies, interviews, focus groups, surveys with open-ended questions, and observations were used to collect data.

Comprehensiveness of Reporting

The comprehensiveness of reporting was variable, with studies reporting details for 2-19 of the total 27 items included in the framework for assessing reporting of qualitative studies (Table S2). All studies specified the number and characteristics of participants. Only 7 studies described how participants were selected. Four studies reported theoretical saturation and on the use of software for coding data. Participant quotations were provided in 21 studies. Twenty studies provided a thick description of results and interpretation in sufficient detail so that readers are able to evaluate the extent to which the findings are transferable to other times, settings, situations, and populations.

Synthesis

We identified 6 themes relating to participants' decisions to donate: compelled altruism, inherent responsibility, accepting risks, family expectation, personal benefit, and spiritual confirmation. Illustrative quotations are listed in Table 2. Three overarching themes dominated the impact of donation and postdonation adjustment of donors: renegotiating identity (fear and vulnerability, sense of loss, depression and guilt, new appreciation of life, and personal growth and self-worth), renegotiating roles (multiplicity of roles, unable to resume previous activities, and hero status), and renegotiating relationships (neglect, proprietorial concern, strengthened family and recipient bonds, and avoidance of recipient indebtedness). We describe renegotiation as the donor's adjustment to changes in his or her identity, roles, and relationships

Theme	Illustrative Quotations					
Compelled altruism	 "I went and saw her on dialysis and said, 'Oh my God.' If anybody had a question [about donation] then go and see them put on a machine."²² "We did not see much of each other we only met at family reunions such as Christmas parties but it was I who told him that I wanted to donate because I wanted him to have a better life than having to be on dialysis treatment for the rest of his life. [sibling]^{r29} "This strong wish to help others is undoubtedly the motivating factor for an individual's decision to donate."³⁴ 					
Inherent responsibility	"This immediate decision making reflects a seemingly spontaneous choice with little deliberation." ¹⁹ "Donors maintained that the decision to donate was rational and informed and no one regarded this decision as 'brave or heroic'; all felt that it was just a 'natural thing to do." ²⁸					
Accepting risks	 "This donor also initially made a straightforward decision to donate but subsequently spent several months contemplating his decision."²⁸ "Nine informants who donated to someone other than their children checked their children's health or blood groups in case the children might need a transplant in the future."³⁹ 					
Family expectation	 "Though the siblings experienced that their decision was autonomous, they were motivated by the expectations from their family."¹⁹ "Because I couldn't have faced my parents if I had refused. I have never liked my sister very much, but once the request was made it was impossible to refuse sort of family and moral duty. I really wish the question of live donation had never come up. I felt a bit like a fish on a hook."²⁷ "Paul did not want to go through the experience of donation he considered it to be his responsibility: "She is my sister, and that was that."²⁴ 					
Personal benefit	 "If she [my wife] is in poor health we won't be able to do things that we want to do. I suppose you could regard it as selfish, but if I can help her from being ill, so that we can continue doing what we like doing, well that's practical."²⁸ "There are some specific psychosocial problems of the donors after LKD [living kidney donation] such as potentially disturbed family hierarchies and disappointment about failure to achieve improvements of the relationship with the recipient."³³ 					
Spiritual confirmation	 "For some participants, donating a kidney was in accordance with their religious beliefs. They viewed the kidney donation as living as a true parishioner or responding to God's will."³⁷ "God told me to do it."⁶⁴ "I had these long soul searches and everything seemed to point to this [decision] this was meant to be."²² 					

Table 2. Illustrative Quotations Representing Living Kidney Donors' Decisions to Donate

Note: Italicized text indicates quotations taken directly from participants of the original studies.

after donation. Illustrative quotations representing the renegotiation of identity, roles, and relationships for living kidney donors are listed in Table 3. A thematic analytical schema of inter-relationships between themes is shown in Fig 1. An educational summary also is available (Item S1).

Decision to Donate

Compelled Altruism

Many donors experienced and understood the detrimental pervasive impact of dialysis therapy on the lives of patients and their families. They primarily were motivated or compelled by the desire to improve the quality of life of their loved one.

Inherent Responsibility

For some donors, the decision to donate was immediate and automatic. This was more evident in parent donors who perceived donation to be a "natural thing" to do for their child. They regarded not donating to their child as incomprehensible and believed it was a normal parental duty.

Accepting Risks

The decision to donate a kidney involved careful consideration of the risks and potential complications. Some donors considered the risks of surgical complications, death, and future health problems, including kidney failure. Some thought about the possibility that their own children may need a kidney in the future and checked their children's blood type.

Family Expectation

Some donors felt obliged to donate due to family expectations, and this was particularly evident in sibling donors. When the potential donor was declared to be the "best match," the donor found it "impossible" to refuse even if they personally did not want to donate. They proceeded with donation to avoid family conflict.

Personal Benefit

A few donors had anticipated gaining a personal benefit because kidney donation would enable the recipient and family to participate in social activities.
 Table 3.
 Illustrative Quotations Representing the Renegotiation of Identity, Roles, and Relationships Among Living Kidney Donors

Themes	Illustrative Quotations
	Renegotiating Identity
Fear and vulnerability	"Thirteen donors felt still burdened at the time of the interview by the constant worry for the recipients' health." ³⁰ "One respondent stated, ' <i>Well, one of my concerns the risk of losing my kidney and going on dialysis myself.</i> " ⁶⁴
	"Others were concerned about donating their good organ now and feared their children might need a kidney later in life."41
	"Furthermore, the worries regarding own health intermittently affected the well-being of the donor." ³⁰ "Both donors and recipients had fantasies of their bodies being disfigured, with particular concern for damage to sexual organs." ³²
	"In particular, the second type with prevailing hypochondriacal tendencies may present themselves often for suspected medical problems and may need special psychological support." ⁶³
	"Maybe it would be a good idea for them to check the donor too once in a while to make sure that everything is okay to just keep in touch with the donor, you know, are you feeling okay, are there any ramifications." ²³
Sense of loss	<i>"You don't feel like a human being!"</i> ¹⁹ "She also expressed a feeling of loss after the donation." ²⁰
	"Following surgery, the experiences of loss were felt by the donor to a much greater extent: the anticipated loss had become a reality, and the defenses of denial, repression, and compensation against this were no longer effective." ³²
Depression and guilt	"Their immediate reactions were characterized by being mentally paralyzed and falling physically and mentally apart."20
Ū	"It was quite a busy period at work, and in the middle of the summer I felt entirely empty. I was depressed, had no energy and felt wholly out of it." ²⁰
	"I guess the full impact really hit home. I just started bawling like a baby for some reason, and at that point I just completely lost it."22
	"Another female donor experienced a period of crying and mild depression and homesickness during the first three days postoperatively." ²⁵
	 "Another suffered from sorrow and mental depression for several months afterwards."²⁹ "Following the transplant she displayed considerable depression and continued to be unable to help herself."³¹ "One of the transplants failed however, shortly after surgery taking place. It is impossible to adequately reflect the devastation ("there was a lot of sadness") experienced when an operation is unsuccessful."⁴¹ "Afterword, about five months, I just felt different in myself, I don't know what the word is, I just didn't feel right. Like I'd be wanting to cry all the time when I don't cry and, stuff like that, and then I thought, 'Oh maybe the whole experience I've come down off this big high, and now it's just hitting me booff!' You know, 'This is what you've done' I don't know if it's a psychological thing after an operation that you go through^{m13} "Now it is awful to go to the cemetery and visit his grave. A piece of me is lying there, too. It is unbelievably strange. You think you did everything that you could do."²⁰
	"A sense of guilt in not having provided a good enough kidney was expressed by one donor."29
New appreciation of life	Regarding own future health, the donors had a positive outlook and expressed few worries. ¹⁹ "Other participants indicated specific changes in lifestyle behaviors as a result of living kidney donation: <i>'I think it was a good thing because it stopped me doing what I was [drugs].</i> " ²²
	"In every way I am better. For realizing how far I could go for others, I am up a notch in life I value things more, big and small things." ²⁵
	"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." ⁴³
Personal growth and self-worth	"For me, being a donor means personal growth. Being a donor makes me so proud. Maybe one becomes less selfish and focuses bit more on others. I hope so!" ¹⁹
	"The giving of a kidney was, for some, an act that increased their self-esteem: 'I really felt good about myself. I did something pretty incredible that most people would never do." ²²
	"I feel better, kind of noble. I am changed. I have passed a milestone in life, more confidence, self-esteem." ²⁵ "Donors expressed positive feelings toward recipients, namely improved emotional life (56%) and having improved quality of life or giving life, and toward themselves of a better self-esteem (31%)." ²⁶
	"To be able to do something for somebody like that (who has been ill for many years) gives me satisfaction and has enriched my life." ³⁶
	"A 40-year old man stated that 'It changes you, you drop your walls, you're more understanding and compassionate of people." ³⁵

(Continued)

 Table 3 (Cont'd).
 Illustrative Quotations Representing the Renegotiation of Identity, Roles, and Relationships Among Living Kidney

 Donors
 Donors

Themes	Illustrative Quotations
	Renegotiating Roles
Multiplicity of	"It's hard being a donor and a carer and a mother."43
roles	"For me, being both a relative and a patient was the greatest challenge. I have always taken care of my brother and felt responsible." ¹⁹
	"Being a living kidney donor most often implies being a patient, a close relative to the recipient and a family member simultaneously." ²⁰
	"A father described that returning to work in itself was fine, but it was a tense period because he was partly at the hospital (caring for the recipient) and partly at home caring for his little daughter." ²⁰
Unable to resume	"As a result I was on sick leave for about four months. I had no strength and could only manage working half
previous activities	days when finally returning to work." ²⁰ "White donors thought potential donors should be aware the pain was minimal, donors are still able to have children, and donation would cause excessive health or financial hardships." ³⁴
Hero status	"Also, the results revealed that the donation was a meaningful event in the donors lives, related to the donors' satisfaction of seeing the improvement of the health of the recipient." ²⁰
	"One of the subjects did compare it to volunteering for a dangerous mission during the Korean War: disarming an unexploded bomb to save the lives of his comrades." ²⁵
	"You sort of come out thinking, 'Well I can do anything. Bring it on!' You're sort of Superman it is probably the biggest thing mentally and physically that I've ever done and probably ever will do. There's no doubt about that in my mind. I can't see anything surpassing it really." ⁴³
	"The best thing that you could ever think of probably the best feeling I've ever had in my life when you actually donate to someone, it is a fantastic experience you just come out of hospital pumped up, really. ^{#3} "Successful donation was described as a 'victory. ^{#44}
	"During this phase they received a good deal of attention from their families and friends and also from strangers who had heard about their sacrifice either by word of mouth or read about it in the local newspapers." ²⁵
	"They initially related these feelings to the extraordinary attention they had received from family, friends, and local news media."35
	"The donors also gained recognition from their co-workers and their religious community."37
	Renegotiating Relationships
Neglect	"She was able to get the sympathy of an older sister who would visit her, rather than her twin, when she came to the hospital, but her brother and both parents spent almost all of their time with the recipient." ⁶¹ "My brother got all the publicity and I was left on my own. I hated him, I wished he was dead." ⁴⁰
Proprietorial concern	"I thought very, very little about what could go wrong to me. I was more worried about my father because he is older than me, and I was afraid that something would happen to him." ¹⁹
	"One sibling donor stated, 'I was telling him, 'Don't do that,' or always at him, which I shouldn't have been, but, you know, I gave it to him." ²²
	"I think the worst feeling I've had would be him not focusing on his health, like physically, maybe overdoing it with things." ²²
	 "Donors' psychological well-being often is dependent on the physical well-being of the recipient."³⁰ "When you see [the recipient] not doing it's really hard when you see your daughter abusing it."⁴³ "It was observed that parent donors, particularly mothers, were consistently genuinely concerned about their child and to a lesser extent worried about themselves. Their need to see their children become healthy appeared to compensate for the loss of their organ."³¹
Strengthened	"My marriage is better, closer now. I was lucky for the opportunity." ²⁵
family and recipient bonds	"Donors emphasized the recognition and support they received from the family members as well as an improved family life." ³⁰ "After giving the kidney, the donor then became much more acceptable to the mother, and he returned to the
	parental home to live during his few weeks of postoperative convalescence."31
	"In a way, we are closer now. We will love each other even more. I think we will be even more attached to each other." ¹⁹
	"All donors described incidences of being helped by the recipient as they struggled to complete activities of daily living."21
	"One pair had experienced kidney rejection and the recipient had to undergo re-transplantation, but this did not affect the relationship between donor and recipient."33
	"The whole experience strengthened relationships of the donors with their recipients and many of them celebrate the transplantation anniversary."37

(Continued)

 Table 3 (Cont'd).
 Illustrative Quotations Representing the Renegotiation of Identity, Roles, and Relationships Among Living Kidney

 Donors
 Donors

Themes	Illustrative Quotations					
Avoidance of recipient	"You wouldn't want him to feel that he's beholden in any way. So I think that you wouldn't want to keep bringing it up in conversation. I think it's time to move on."28					
indebtedness	"It also appeared from the interviews that the donors' experiences were free from expectations of repayment or gratitude from the recipient." ³⁶					
	"The majority of donors, however, were in favor of anonymity."36					

Note: Italicized text indicated quotations taken directly from participants of the original studies.

Particularly for spousal donation, both the recipient and donor believed they would gain an improvement in quality of life. Some donors expected that kidney donation would improve their relationship with the recipient.

Spiritual Confirmation

Some believed donation was a higher calling for their lives as a way to help people who were suffering. Being a match was perceived by a few as a "confirmation" from God that they should be donors.

Renegotiating Identity After Donation

Kidney donation had an impact on the donor's identity, self-perception, and values. For many donors, they developed a new appreciation of life and experienced growth and increased self-worth, but some felt a sense of fear and vulnerability, loss, and depression and guilt.

New Appreciation of Life

After kidney donation, many donors expressed a new appreciation of life and had a positive outlook for the future. They valued life more and chose not to take things for granted. For some, they adopted a more productive and healthier lifestyle.

Personal Growth and Self-worth

The act of donation often was described as a unique rewarding and meaningful experience that profoundly changed the donor's self-perception and identity. The donors believed they gained an increased sense of self-worth, confidence, and compassion toward others.

Fear and Vulnerability

After donation, donors had a heightened concern about potentially having kidney failure and needing

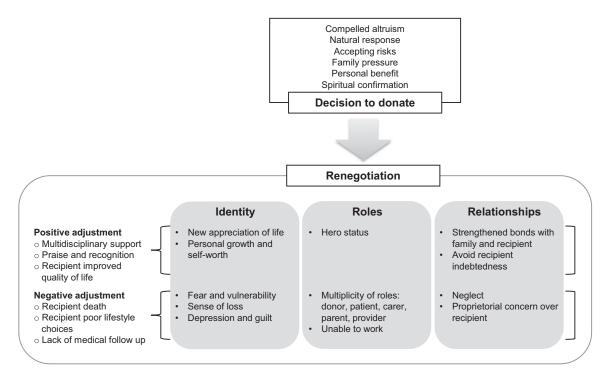


Figure 1. Thematic schema of living donor experiences and perspectives: renegotiating identity, roles, and relationships after kidney donation.

dialysis. They were cautious and worried about their own physical well-being and felt particularly susceptible to ill health. Some donors also were concerned about the impact of donation on sexual function and fertility. A number of donors urged for vigilant and ongoing medical follow-up after donation because this would provide reassurance and mitigate the risks of potential health problems.

Sense of Loss

A few studies found that donors felt a sense of loss after donation. One participant expressed that they felt "dehumanized."

Depression and Guilt

Some donors felt depressed, anxious, and distressed after donation. For many, the emotional angst was only transitory and occurred within the postsurgical recovery period. However, a few donors described being in a state of sorrow and depression for a long period, more than several months. However, this usually depended on the recipient outcome, the perceived care they received in the hospital, or their ability to return to work and normal activities. If the transplant was unsuccessful or the recipient died, donors felt devastated and "mentally paralyzed." Some harbored despair and guilt, believing they had not given a "good enough" kidney.

Renegotiating Roles After Donation

Kidney donation affected the donor's perceived role within the family and in the community. They appreciated the opportunity to help their recipient and some received recognition as a hero. However, some donors believed they had to contend with new and multiple roles in the family after donation or struggled to fulfill their role as a provider.

Hero Status

Donors were metaphorically described as a soldier or "superman" and were perceived by others to be self-sacrificing individuals. Some received praise and attention and gained recognition from their community.

Multiplicity of Roles

For some family donors, contending with multiple roles after donation as a patient, donor, carer, family provider, and homemaker was challenging. Having to simultaneously fulfill the roles of a carer and a recovering patient was stressful and impeded their recovery from donation.

Unable to Resume Previous Activities

As a family provider, some donors were unable to work due to fatigue and weakness. This caused financial hardship in some families.

Renegotiating Relationships After Donation

Donors experienced a change in relationship with the recipient or family. Most donors reported an improved and strengthened relationship. However, some felt they became more anxious about the recipient's health and lifestyle choices.

Strengthened Family and Recipient Bonds

Some donors believed the transplant improved and strengthened relationships between spouses and siblings and parent-child bonds. One donor believed he gained approval from his parents because he donated.

Avoidance of Recipient Indebtedness

Some donors did not expect repayment or gratitude from donors and were even conscious that recipients may feel unduly indebted to them. As such, donors actively avoided frequent mention of the donation and sought to "move on" with their lives.

Neglect

Some sibling donors believed that the recipient received more attention and felt hurt and neglected by their family members. This led to jealousy and rivalry between siblings.

Proprietorial Concern

After donation, many donors were worried and concerned about their recipient and potential transplant failure. Particularly if the donor and recipient were close, the donor's well-being "depended" on the well-being of the recipient. Donors had high expectations and hope for recipients to lead better quality, healthier, and productive lives. They felt frustrated and angry if they perceived the recipient was not looking after health as they ought, especially because they had given their own organ to the recipient. A few recognized that this drove them to try and control their recipient's lifestyle choices.

DISCUSSION

Kidney donation has a profound and multifaceted impact on the lives of donors, who have to renegotiate their identity, roles, and responsibilities posttransplant. Positive adjustment in donors was characterized by a new appreciation of life, personal growth and self-worth, hero status, strengthened bonds with family and recipient, and avoiding recipient indebtedness, which was facilitated in part by multidisciplinary support, recognition, and improved outcomes of the recipient. Negative adjustment encompassed fear and vulnerability, sense of loss, depression and guilt, multiplicity of roles, inability to work, neglect, and proprietorial concern over the recipient, which sometimes was intensified by poor recipient outcomes or death and lack of medical follow-up for donors.

In this study, we performed a comprehensive search and independent appraisal of study reporting. We used software to code the data and record an auditable development of themes; which can be used to assess whether these reflect the findings of the primary study. We also have produced a new analytical framework that incorporates concepts relating to positive and negative adjustment in living kidney donors integrated within the themes of renegotiating identity, roles, and responsibilities. Some of the included studies involved a small number of participants; however, qualitative research does not aim to achieve statistical representativeness and generalizability. Often, information-rich participants are selected to provide rich insight about the phenomena being studied. Similar concepts identified across studies suggest that the findings are potentially transferrable to other settings. A limitation of the study is that we did not access the original transcripts and observation notes, although this is not standard practice in the synthesis of qualitative studies. We excluded non-English articles and therefore the transferability of our findings to non-English-speaking countries is uncertain.

Most donors indicated that they were motivated by a desire to improve the quality of life of the recipient. However, the decision to donate was influenced by a range of beliefs and attitudes. Current guidelines recommend that donors should be free from "coercion." However, it is argued that the complete absence of coercion or obligation is unrealistic because the act of donation is "life saving" or perceived to be the only option.⁴⁵ Donors are motivated by a desire to help, increased self-esteem from the opportunity to do good, identification with the recipient, self-benefit from the relative's improved health, and a feeling of moral duty.⁴⁶ These need to be considered in the development of more extensive guidance for assessing donor motivations and decision making around donation. Some sibling donors expressed that they perceived a family obligation and agreed to undergo donation to avoid tension within the family. However, with less emphasis on HLA antigen mismatch, this perceived obligation might be minimized. We support past statements that describe the value of "donor advocates" who are independent from the recipient assessment team to act on behalf of potential donors to ensure that donors are willing and free from undue coercion and also to buffer against pressure, conflict, and tension between the potential donor and his or her family. A recent article written by physicians who have been kidney donors emphasizes that the decision to donate is a shared responsibility among the donor, the donor's physician, and the transplant center.⁴⁷

Although the act of donation was regarded by many donors as rewarding, kidney donors had a heightened sense of vulnerability and fear about potential health problems. Some studies have suggested that donors may be at risk of hypertension and proteinuria.^{48,49} Data to date support no increase in risk of major cardiovascular events,⁵⁰ and there is no evidence of increased long-term mortality in kidney donors.51-54 Depression also has been identified in this population. Our findings highlight the importance of offering regular on-going health monitoring and follow-up for all living kidney donors to manage potentially modifiable risk factors and mitigate the risks of health problems and psychological harms. Specific strategies may include giving opportunity for regular or "asneeded" assessment of donors by telephone or e-mail, a donor hotline, access to donor-specific counseling services, and active outreach in the event of recipient complications or death. Further evaluation and refinement of these strategies is suggested.

Data for long-term living donor outcomes are lacking, and what is concerning is the sparse data for donors who have risk factors for kidney failure, including hypertension and being overweight.6,55 Prospective long-term studies and efforts to collect and analyze registry data are urgently needed to inform the screening and management of living donors and increase the capacity of potential donors to make an informed choice and weigh the risks involved in donation. However, resource and feasibility issues need to be considered. For quality-of-life outcomes, living donor quality of life has been assessed with generic instruments, including the Medical Outcomes Study 36-Item Short Form Health Survey^{16,56} and World Health Organization quality-of-life questionnaire.⁵⁷ However, we suggest that a quality-of-life tool specific for living organ donors is needed to include donor-relevant domains that may not be captured in existing instruments. Specific issues that would impair donor quality of life include contending with multiple roles, feelings of neglect, sense of vulnerability to health problems, proprietorial anxiety over the recipient, and tendency to seek to control the recipient's lifestyle choices.

Qualitative research conducted with living donors typically has involved donors who have a preestablished, usually familial, relationship with the recipient. However, this review has identified important areas that have received little attention in the current literature, including donor concerns regarding the implications for donor insurance policies,^{58,59} disintegration of relationships (separation or divorce between spousal donors), and postdonation follow-up and continued interaction with the medical environment. A broader understanding of living kidney donor perspectives can inform health services and policy of ways to promote the best outcomes for potential and actual living kidney donors.

Research also is needed to elicit the experiences and perspectives of living donors who have donated a kidney in paired kidney exchange (in which a live kidney donor who is incompatible with the intended recipient donates to a compatible recipient in order for another donor to donate to the original donor's recipient)⁶⁰ and anonymous nondirected donation programs,⁶¹ which are important emerging types of donation with complex psychosocial implications.

Living kidney donation can confer survival and quality-of-life benefits to patients with end-stage renal disease. However, vigilant monitoring of living kidney donors is needed to minimize the risk of developing health problems and psychological harms. Strategies that aim to safeguard against unwarranted coercion and maximize living kidney donors' health resilience, capacity to negotiate multiple roles as a patient and carer, emotional fortitude, and ability to have balanced expectations and relationships with the recipient and the family are needed to ultimately protect the safety and well-being of living kidney donors.

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SUPPLEMENTARY MATERIAL

Table S1: Search strategies.

Table S2: Comprehensiveness of reporting.

Item S1: What are the experiences of living kidney donors? An educational summary.

Note: The supplementary material accompanying this article (doi:10.1053/j.ajkd.2011.11.043) is available at www.ajkd.org.

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