



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 tension¹³⁻¹⁵ and guilt,^{13,16} with donors additionally reporting experiencing neglect^{13,17-19} and proprietorial 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

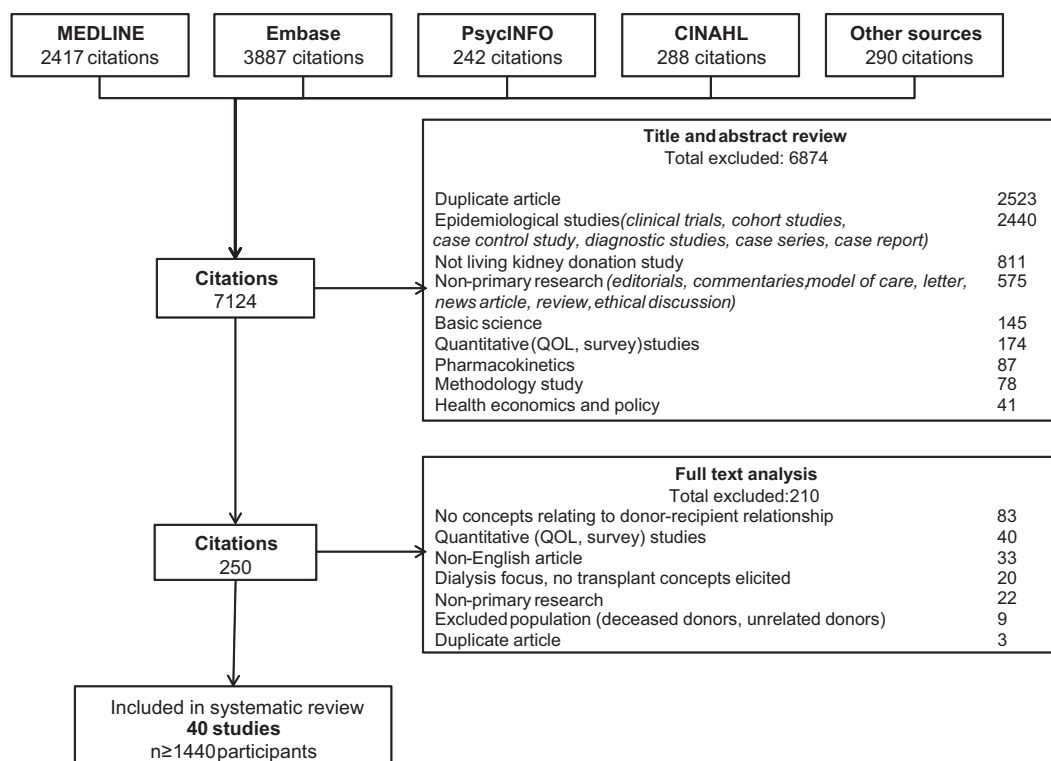


Figure 1. Search results. Abbreviation: QOL, quality of life.

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