



## Motivations, Challenges, and Attitudes to Self-management in Kidney Transplant Recipients: A Systematic Review of Qualitative Studies

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**Background:** Kidney transplantation offers better outcomes compared to dialysis, but requires patients to adhere to an ongoing and complex self-management regimen. Medication nonadherence remains a leading cause of transplant loss, and inadequate self-management undermines transplantation and other health outcomes. We aimed to describe kidney transplant recipients' motivations, challenges, and attitudes toward self-management.

**Study Design:** Systematic review and thematic synthesis of qualitative studies.

**Setting & Population:** Kidney transplant recipients.

**Search Strategy & Sources:** MEDLINE, EMBASE, PsycINFO, and CINAHL were searched to October 2014.

**Analytical Approach:** Thematic synthesis.

**Results:** 50 studies involving 1,238 recipients aged 18 to 82 years across 19 countries were included. We identified 5 themes: empowerment through autonomy (achieving mastery, tracking against tangible targets, developing bodily intuition, routinizing and problem solving, and adaptive coping), prevailing fear of consequences (inescapable rejection anxiety, aversion to dialysis, minimizing future morbidity, trivialization and denial, and defining acceptable risks), burdensome treatment and responsibilities (frustrating ambiguities, inadvertent forgetfulness, intrusive side effects, reversing ingrained behaviors, and financial hardship), overmedicalizing life (dominating focus, evading patienthood, and succumbing to burnout), and social accountability and motivation (demonstrating gratitude toward medical team, indebtedness to donor, and peer learning).

**Limitations:** Non-English articles were excluded.

**Conclusions:** Self-efficacy and social accountability are motivators for self-management, although adherence can be mentally and physically taxing. Multicomponent interventions incorporating personalized care planning, education, psychosocial support, decision aids, and self-monitoring tools may foster self-management capacity and improve transplantation outcomes.

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**INDEX WORDS:** Self-management; medication adherence; patient-centered care; qualitative research; transplant recipient; kidney transplantation; chronic condition; end-stage renal disease (ESRD).

### Editorial, p. 357

Transplantation outcomes are largely determined by the capacity of transplant recipients to adhere to a complex and ongoing self-management regimen to minimize the risks for transplant loss and future comorbid conditions.<sup>1,2</sup> Nonadherence to immunosuppression results in a 7-fold increase in transplant failure,<sup>3</sup> yet the rate of medication nonadherence in kidney transplant recipients is estimated to exceed 30%.<sup>3-5</sup> This suggests that more effective strategies are needed to empower patients for self-management.<sup>6,7</sup>

Self-management is defined as “the tasks that individuals must undertake to live with one or more chronic conditions, [including] having the confidence to deal with medical management, role management and emotional management of their conditions.”<sup>8,p57</sup> For kidney transplant recipients, these tasks include adhering to medications, monitoring for signs of rejection, keeping appointments with specialists, maintaining adequate

hydration, undertaking cancer screening, exercising sun protection, and consuming a low-salt, low-fat, and low-cholesterol diet.<sup>1</sup>

The risks of long-term immunosuppression include cardiovascular disease, cancer, diabetes, osteoporosis, infection, and weight gain.<sup>9-12</sup> Thus, self-management

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tasks such as taking immunosuppressants may be perceived as burdensome if the potential adverse effects conflict with patients' preferences and goals.<sup>13</sup> Risk factors for poor adherence to immunosuppression include longer time posttransplantation, depression, financial strain, younger age, social isolation, and low cognition.<sup>14-18</sup> However, patient perspectives on self-management, which might explain adherence and other self-management decisions and behaviors, are less well understood.

Qualitative studies can generate in-depth insights into patients' values, knowledge, and beliefs that influence behaviors and choices in transplantation self-management.<sup>19</sup> Most studies have focused on a single self-management task (eg, medicine taking) or population. However, investigating self-management as a multidimensional construct encompassing the conglomerate of behaviors may yield more comprehensive insights.<sup>20,21</sup> A systematic review of qualitative studies can elucidate a broader understanding of patient perspectives underpinning all posttransplantation self-management responsibilities across different settings. This review aims to describe the attitudes and beliefs about self-management among kidney transplant recipients, which is likely to inform clinical care, shared decision making, and education resources and programs to promote capacities for self-management.

## METHODS

This study follows the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework.<sup>20</sup>

### Selection Criteria

We included qualitative studies that described adult kidney transplant recipients' knowledge, attitudes, and experiences pertaining to transplant self-management. Self-management tasks could encompass medicine taking, monitoring for signs and symptoms of rejection, attending follow-up clinics, fluid intake, sun protection, cancer screening, diet, and physical activity.<sup>1</sup>

### Data Sources and Searches

Search strategies are provided in [Item S1](#) (provided as online supplementary material). We conducted searches in MEDLINE, EMBASE, PsycINFO, and CINAHL (Cumulative Index to Nursing and Allied Health Literature) from database inception to October 2014, as well as Google Scholar and reference lists of relevant studies and reviews. Two authors (N.J.J. and C.S.H.) screened titles and abstracts of search results and excluded those that did not meet selection criteria. Full texts of potentially relevant articles were then assessed for eligibility.

### Comprehensiveness of Reporting

The transparency of reporting of each qualitative study was evaluated independently by N.J.J. and C.S.H. using the Consolidated Criteria for Reporting Qualitative Health Research (COREQ),<sup>20</sup> a framework that includes criteria specific to the research team, study methods, study context, analysis, and interpretations.

### Data Analysis

We used thematic synthesis as described by Thomas and Harden.<sup>22</sup> Participant quotations and text under the "results/

findings" or "discussion/conclusion" section from each of the included studies were entered into HyperRESEARCH, version 3.7.1 (ResearchWare Inc, 2015), software for qualitative data management. N.J.J. read each study, conducted line-by-line coding of the findings, and inductively identified concepts relating to kidney transplant recipient perspectives on self-management. Concepts were compared and translated across studies by adding coded text into existing concepts or creating additional codes for new concepts. Similar codes were grouped into themes and sub-themes. After coding was completed, the software was used to generate a report of all codes with the corresponding text. Three authors (N.J.J., C.S.H., and A.T.) read the papers independently to check that all data were included in the interpretation, preliminary analysis, and analytical framework. This form of investigator triangulation ensures that all themes captured the full breadth of available data. Patterns and relationships within and across themes were mapped to develop an analytical thematic schema. We also cross-tabulated themes with the relevant self-management tasks as reported across studies.

## RESULTS

### Literature Search

Our search yielded 5,348 articles ([Fig 1](#)). Of these, 50 articles from 19 countries involving 1,238 adults were included ([Table 1](#)). The age range of recipients was 18 to 82 years and 58% were men. In the 31 studies that reported donor type, 355 (44%) patients had received a living donor kidney and 443 (56%) had received a deceased donor kidney.

### Comprehensiveness of Reporting

The comprehensiveness of reporting was variable because studies reported 4 to 22 of the 26 items in COREQ ([Table 2](#)). All studies reported sample size and provided participant quotations. Fifteen studies (30%) reported on theoretical saturation. The participant selection strategy was stated in 19 (38%) studies. Investigator triangulation (when multiple researchers were involved in data analysis) was reported in 26 (52%) studies. Of 18 studies conducted in non-English-speaking countries, one study reported on the language in which data were analyzed.

### Synthesis

We identified 5 main themes reflecting the perspectives of kidney transplant recipients on self-management: empowerment through autonomy, prevailing fear of consequences, burdensome treatment and responsibilities, overmedicalizing life, and social accountability and motivation, as described next. Selected quotations and all contributing studies for each theme are presented in [Table 3](#). Conceptual links among themes are presented in [Fig 2](#). A cross-tabulation of themes with the self-management tasks is provided in [Fig 3](#).

#### *Empowerment Through Autonomy*

*Achieving mastery.* Gaining confidence in self-management helped patients feel that they were

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