**The Work of Being an Adult Patient with Chronic Kidney Disease: A Systematic Review of Qualitative Studies**

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**ABSTRACT**

**Introduction:** Chronic kidney disease (CKD) requires patients and caregivers to invest in self-care and self-management of their disease. We aimed to describe the *work* for adult patients that follows from these investments and develop an understanding of burden of treatment (BoT).

**Methods:** Systematic review of qualitative primary studies, that builds on EXPERTS 1 Protocol, PROSPERO: CRD42014014547. We included research published in English, Spanish and Portuguese, from 2000 to present, describing experience of illness and healthcare of people with CKD and caregivers. Searches were conducted in MEDLINE, Embase, CINAHL Plus, PsycINFO, Scopus, SciELO, and Redalyc. Content was analysed with theoretical framework using middle-range theories.

**Results:** Searches resulted in 260 studies from 30 countries (5115 patients and 1071 carers). Socio-economic status was central to the experience of CKD especially in its advanced stages when renal replacement treatment is necessary. Unfunded healthcare was fragmented and of indeterminate duration, with patients often depending on emergency care. Treatment could lead to unemployment, and in turn, to un- or under-insurance. Patients feared catastrophic events because of diminished financial capacity and made strenuous efforts to prevent them. Transportation to and from haemodialysis centre, with variable availability and cost, was a common problem, aggravated for patients in non-urban areas, or with young children, and low resources. Additional work for those un- or under-insured included fund-raising. Transplanted patients needed to manage finances and responsibilities in an uncertain context. Information on the disease, treatment options, and immunosuppressants side-effects was a widespread problem.

**Conclusions:** Being a person with end-stage kidney disease always implied high burden, time-consuming, invasive and exhausting tasks, impacting on all aspects of patients and caregivers’ lives. Further research on BoT could inform healthcare professionals and policy makers about factors that shape patients’ trajectories and contribute towards a better illness experience for those living with CKD.

**Article summary**

* We analysed data with a coding framework supported by middle-range theories to understand the work involved in being a person with CKD.
* Comprehensive inclusion of publications in English, Spanish, and Portuguese, which may enhance the transferability of our findings.
* The variety of methodologies, quality of reporting, and heterogeneity of perspectives make synthesis difficult.

**Key words:** chronic kidney disease, burden of treatment, treatment burden, haemodialysis, transplantation, chronic illness

**INTRODUCTION**

Chronic Kidney Disease (CKD) contributes significantly to global morbidity and mortality.1-4 Even in its early stages, the risk of death, cardiovascular events, cerebrovascular disorders, hospitalization, reduced health-related quality of life, anxiety, depression and suicidal ideation is increased.1-6

Worldwide, about 500 million people are affected by CKD; about 80% of these live in low and middle-income countries (LMIC); an estimated 3 million people with end-stage kidney disease (ESKD) receive renal replacement therapy (RRT) with either dialysis or transplantation.1 7 8 The number of people receiving RRT is increasing and will more than double by 2030, but a significant number of people without access to this type of live-saving treatment will remain.9 In 2010, at least 2.28 million people might have died because of lack of access to RRT, mostly in LMIC in Asia, Africa, and Latin America.9

Much is now known about the pathophysiological and treatment trajectories of CKD, and about the associated burden of symptoms experienced by patients. More recently, there has been increasing interest in the way that complex long-term conditions require patients and their carers to invest in self-care and self-management of their disease.10-15 The work for patients and carers that follows from these investments, including medication management, medical visits, laboratory tests, lifestyle changes, and monitoring in addition to the activities done as part of life, is here termed burden of treatment (BoT), which adds to the burden of symptoms (BoS).10 13 16 Research on BoT has focused on long-term conditions such as diabetes, chronic obstructive pulmonary disease and chronic heart failure with the development of analytic framework and patient created taxonomies.10 16-27 Patients and carers are expected to actively participate in managing both index conditions and comorbidities and, depending on their resources or lack thereof, they often need to negotiate or renegotiate the responsibilities that healthcare providers and healthcare systems assign to them.13 28 29 Patient and carers’ experience in managing the disease and its treatment, including their choices and expectations, is affected by structural, relational and resilience factors; the interactions among these factors remain understudied.30 The aim of this study is to develop specific understanding of treatment burden experienced by people with CKD and ESKD extending it to experiences of uninsured and under-insured patients in LMIC.

**METHODS**

This is a systematic review of primary qualitative studies, which builds on the published EXPERTS1 Protocol and its meta-review of qualitative reviews.30 31 PROSPERO registration number is CRD42014014547. This review follows the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework.32 We interrogated a subset of qualitative primary research papers concerned with CKD identified by EXPERTS1 qualitative meta-review to understand the dynamics of patient experience of complexity and treatment burden in long-term life-limiting conditions. EXPERTS1 search was updated and expanded to Spanish and Portuguese language literature.

**Eligibility, inclusion and exclusion criteria**

Eligibility criteria for study inclusion were developed using the PICO (participants, interventions, comparators, and outcomes) framework (Table 1). Inclusion criteria were primary qualitative and mixed-method studies of adult patients diagnosed with CKD in any stage and their formal or informal carers; in any type of treatment or healthcare provision; not limited to comparative studies; with qualitative data on the patients and carers’ experiences on any aspect of CKD, in any stage, and its treatments; in English, Spanish and Portuguese. Following the EXPERTS1 protocol, studies were excluded if they were of other EXPERTS1 index conditions; if they reported results of treatments, interventions, tests or surveys; were guidelines, discussions of the literature or editorials, notes, news, letters, and case reports; if the experiences described by patients and carers could not be clearly discriminated.31 Studies describing experiences of children with CKD were excluded because their BoT may be significantly different from that of adult patients. The year of publication 2000 onward was established to include current treatments.

**Study selection**

# A first search for the EXPERTS1 meta-review was conducted in MEDLINE, Embase, CINAHL Plus, PsycINFO, and Scopus. For this review, searches were updated using the same databases and expanded to include studies published in Spanish and Portuguese with additional searches in the Iberoamerican databases SciELO (Scientific Electronic Library Online), and Redalyc (Red de Revistas Científicas de América Latina y el Caribe, España y Portugal). Searches were completed by April 2017 and identified papers published between 1 January 2000 and March 2017. Search strategy is included in Appendix 1. For a first set of studies, titles and abstracts were independently screened by AC, MM and CRM, disagreements resolved by JH. Full text papers (n=1238) were obtained and screened by JH, KAL and MM; disagreements resolved by KH or AC. Of 606 articles, 191 were related to CKD. For a second set, updated results in English and studies in Spanish and Portuguese were screened by JR, JPA, disagreements resolved by FC. Two authors (JR, JPA) assessed papers against the Critical Appraisal Skills Program (CASP) qualitative research checklist.33 As there is no accepted criteria for the exclusion of qualitative studies based appraisal score, we did not exclude studies based on quality. See Figure 1 for screening and selection process.

**Data extraction and analysis**

Data outlining study characteristics were extracted into table 2. Manuscripts were entered into Atlas.Ti v7.5.12 (Scientific Software Development GmbH). The results sections and participant quotations of the primary studies were analysed line-by-line using directed content analysis, sometimes called framework analysis.34 The coding frame drew on concepts from the Burden of Treatment Theory and the Cognitive Authority Theory.18-21 29 35 36 Coding was conducted by JR and CRM, with a third party involved for disagreements (JPA), and reviewed and discussed by two researchers (AC, MM). Refinement of the coding frame and analysis was iterative, codes were identified or merged reading the result sections of primary studies and consulting the theoretical framework. Investigator triangulation (comparison of results of two or more researchers) was used to capture relevant issues, reflect participants’ experience as reported, and ensure the credibility of the findings.

**Patient and Public Involvement**

Patients and/or public were not involved in the development of the research question. To ensure wide dissemination of this systematic review, it is published in peer reviewed open-access journal and presented in research meetings.

**RESULTS**

Combined searches yielded 5407 citations and resulted in 260 studies from 30 countries included in the final analysis. A total of 5115 patients and 1071 carers were included. Countries most frequently represented in the studies were: United States with 52 (20%), United Kingdom with 46 (18%), Brazil with 28 (11%), Australia with 25 (10%), Canada with 20 (8%), Sweden with 19 (7%), New Zealand with 8 (3%), and Iran with 7 (3%) studies. Most studies (n=193, 74%) described the experiences of patients with ESKD, in dialysis or conservative treatment, 28 (11%) studies reported on transplanted patients, 17 (6%) studies referred to patients with CKD stages 1-4, and the remainder studies described experiences of patients with CKD in all stages. Table 2 shows characteristics of studies included in the review, table 3 shows illustrative quotations, table 4 shows summary of results, and table 5 shows main challenges related to BoT.

**Structural inequalities**

*Access to care*. Poverty and other socio-economic disadvantages such as unemployment or poor housing conditions were defining factors for lack of treatment or interrupted care.37-52 Living as a person with CKD and ESKD always implied some degree of financial burden, from having to pay for the whole dialysis treatment or transplantation surgery to out-of-pocket payments of incidentals, even in countries with universal coverage.35 47-49 51 53-63 Poorly funded or unfunded healthcare resulted in fragmented treatment across healthcare systems.47 48 64 Although patients who had difficulties affording treatment were naturally more concerned with accessing healthcare than in improving services, they recognized fragmentation and lack of integration as important problems.40 45 48-51 Where government or private insurance coverage of ESKD treatment was limited, e.g. Mexico or India, patients paid for some or all the following: vascular access, hospitalization, medical visits, haemodialysis sessions, medication, tests, prescribed food, transport and meals.45 47-50 60 65 In such settings, patients received dialysis treatment only if they could afford it or when they had access to free sessions.45 47-50 60 65 Medication was sometimes counterfeit, obtained on the black market, as legitimate medication was beyond patients’ reach.49 For the uninsured, dependence on emergency care added uncertainty and risk, whatever their treatment modality, as in the case of many undocumented and uninsured immigrants in the United States.35 47-49 52 66 In countries with poor healthcare infrastructure, patients reported shortage of public specialized hospitals, long delays to undergo examinations, limited number of haemodialysis machines available, lack of ward space, or poor bed conditions in hospitals, e.g. poor hygiene, worn-out mattresses, shortage of linen; to avoid delays, patients sometimes had tests performed by private providers.40 50 60 67 68

When home dialysis was available, patients had to pay for transport to training, appointments, and other check-ups; moreover, some equipment, supplies, increased utility bills, and home modifications represented unexpected expenses.51 53 61 69-73 In countries with coverage of RRT, for patients whose first language was different from that where treatment was received, as in the case of migrants, communication was a barrier for discussions with healthcare professionals; family members and neighbours acted as translators at appointments.53 74-76 Where language was shared, communications between clinicians and patients of different ethnic origins—for example, Australian Aborigines and New Zealand Maoris—was often itself a source of conflict and disadvantage, because of prejudice.53 57-59 77-82

In some countries, the transplantation procedure could be particularly expensive, even at public hospitals.35 47-49 66 83 Moreover, patients sometimes found that the expensive immunosuppressants necessary after the transplant were not covered by their insurance; other patients who obtained information about the high costs of immunosuppressants and realising that they could not afford them, were forced to continue with dialysis until it failed.49 83-85 In Mexico, structural constraints resulted in transplanted patients being sent back to small peripheral clinics with no transplantation expertise, increasing the risk of iatrogenic or poorly managed complications.83

*Housing conditions*. Unsuitable housing was a barrier to home dialysis if it could not accommodate equipment, and was impossible without an adequate electricity supply.51 61 In rented accommodation, landlords might not approve of necessary modifications. Home dialysis was not a treatment option for those with no fixed abode.51 61 70 86

*Employment status*. Patients who were physically able to continue working often had informal or temporary jobs, with diminished income; others were forced into unemployment, leading to new financial problems.39 45 52 60 69 72 87-91 Unemployed patients in the United States were covered by government or state schemes; however, this coverage either diminished or ceased if they found work with a new insurance.35 52

**Patient workload**

*Self-care*. People with CKD and ESKD had complex medication regimens managed through dispensing aids, daily activities associated to medication taking such as meals, family support, or a combination of these.40 46 71 86 92-106 Anticipating dialysis, patients underwent vascular access, a way to reach the blood for haemodialysis, undergoing minor surgery and care needed to be taken to prevent infections or clotting.66 107-110 To care for their vascular access, patients kept the access area clean, changed bandages, restricted themselves from lifting heavy objects and were alert for pain or hardness in the area.108 111

Patients controlled their diets and fluid intake between dialysis sessions, and managed food cravings and thirst with strategies such as thinking of the potential detrimental consequences of drinking water, avoiding thoughts and behaviours that could trigger thirst, and modifying social activities to minimise exposure to hot weather, social pressure and temptation to intake certain foods or fluids.46 63 112-120 Women also faced potential family conflicts if they followed prescribed diets.45 62 121-124 In certain cultures, including immigrants who preserved their customs in other countries, the perceived association of a rich diet and wealth acted as a barrier to adherence to a restrictive diet, essential to self-care, as patients feared being stigmatized as poor.62 121 125

*Travel and time management*. People with ESKD travelled to haemodialysis centres three times a week, received treatment for several hours, and then transported themselves home again; very often, transportation represented a problem for patients because of pick-up delays, long distances, or high costs.15 47-49 53 76 86 126-133 Patients receiving dialysis arranged their daily activities between treatment sessions, adjusted the timing and intensity of their activities to their fatigue, and tried to schedule medical appointments all on one day to avoid further interactions with the healthcare system.55 134-145 The treatment was seen by most patients as an emotional and time imposition that caused boredom and frustration.63 146-152 Time was often spent waiting for visits, prescriptions, and tests.55 134-145 153 Parents also arranged child care while they were in sessions, or had to travel for treatment.49 53 55 154 155

*Home dialysis*. For patients receiving home dialysis, training was required which necessitated extended periods of leave from work.61 70 156-158 They and their families had to adapt their home to accommodate equipment and materials, and spent more time cleaning in case health workers assessed their housing conditions.152 158-162 Tasks associated included managing treatment at set times each day, recording blood pressure and body weight, titrating medications, and adopting aseptic techniques, as well as adhering to diet and fluid restrictions.156 157 163 In the case of developing peritonitis, workload increased as antibiotics had to be reconstituted and injected.156 157

*Pre-transplantation adaptation*. People with ESKD adjusted to being on the transplant waiting list and prepared for the possibility of receiving a kidney from a deceased donor at any time.43 115 133 164-170 The tasks included hospital visits, several investigations and tests, saving money for the operation, and maintaining robust health; many potential recipients felt overwhelmed by all that was necessary.132 133 164 165 170-173 Talking to others about their requirement for a kidney transplant involved making the request itself to potential living donors, educating people about CKD, treatment options and donation.39 47 164 174

*Post-transplantation adjustment*. After transplantation, patients’ workload included financial and occupational changes resulting from a new type of treatment and status, managing complex medication regimens and managing social relations.84 85 175-180 These tasks had to be balanced against the work of safeguarding access to healthcare, organising their disability insurance, interacting with healthcare providers, managing symptoms, monitoring medication side effects, and managing self-care in relation to diet, fluid and physical activity.84 85 175-180 Although transplantation was seen as a route back to normality, it was laden with ambiguous feelings towards the donor, unanticipated challenges in forming or maintaining relationships, financial worries, the responsibility of supporting their family, disappointments when side effects were noticed, and a prevailing prognostic uncertainty.83 85 175-177 181-186

*Navigating health care structures*. Very often, patients had to identify and call on the appropriate institutions to obtain a diagnosis, laboratory exams, treatment, or coverage; contacting several public and private healthcare providers, social insurance offices, charity organisations and NGOs.48 49 125 161 In settings with coverage of RRT, socio-economically disadvantaged patients could also find it difficult to access financial support and navigate the social support system, which resulted in not receiving the assistance to which they were entitled.51 Lack of continuity of care contributed to patients using services without sufficient expertise in CKD or ESKD, such as emergency departments or peripheral health centres.49 101 The efficiency focus of the medical system was perceived by patients and professionals as a barrier to a personal connection; moreover, patients also recognised professionals’ dismissive attitudes toward patients’ experiential knowledge.173 102

*Negotiating costs and fund-raising*. Those patients and carers in countries with limited health coverage needed to perform additional work; poor families sold goods, products or services, organized raffles to collect money, or obtained loans.47-49 125 They also contacted treatment centres, other patients, hospitals, and non-government organizations to ask for free dialysis sessions or medication. For this reason, disadvantaged people were advised by healthcare staff on how to seek help in charities and advocacy organizations.47 In more affluent settings, patients also struggled to negotiate coverage of extra expenses, such as those related to home dialysis or conservative management.51 161

**Capacity**

*Physical and mental capacity*. The ability of people with ESKD to carry out daily activities, including their paid job, was limited by symptoms associated with the disease and dialysis treatment, such as pain, fatigue, anxiety, depression, and sexual problems,37 44 55 63 90 96 138 140 154 187-201 sometimes overlooked by health professionals.58 94 101 202-204 When in poor physical health, patients relied on wider family networks and neighbours to help with activities related to BoT such as scheduling and attending medical appointments, arranging transportation to those appointments, ordering and arranging medical supplies, and training; also, other daily tasks such as food preparation, or shopping.37 118 161 205-209 Carers were involved in the dialysis procedure, accompanying patients to dialysis and responding to psychosocial needs.45 69 97 129 141 143 161 210-216 Patients’ capacity to carry out the activities related to healthcare were affected by insufficient financial resources and the fear of catastrophic consequences, such as death because of lack of dialysis treatment or immunosuppressive medication in the case of transplanted patients.47 49 52 217 218

*Managing information*. Obtaining information on the disease and treatment was a significant burden for patients and carers. Patients reported that their information on the disease and treatment options was often insufficient or difficult to comprehend, particularly during the early stages of their trajectory, independent of income or coverage level.38 50 57 58 61 63 64 77 92 109 121 125 127-131 188 205 219-230 Patients may not have asked for clarification for fear of not understanding or because they did not even know what to ask; the desire for more patient-centred care were widely expressed. Short clinic visits, unknown technical jargon, and high levels of anxiety were barriers to accessing information.61 102 223 231-234 Other patients could sometimes supply information about dialysis options, travelling, hygiene regimens, dietary restrictions, benefit advice, timing of treatment, and pain management.117 174 235-238 For organ donation and transplantation, people usually received information through discussions with other patients, providers, social workers, financial representatives, the internet, and, in affluent populations, informative meetings.117 174 235-238 In relation to transplantation, patients reported they needed practical information about the unexpected side effects of immunosuppressive medication; most frequently mentioned were higher risk of cancer, infections, weight gain, and fragile skin.178 184 185 239-242 Other information needs for transplanted patients included coping with emotions related to the transplant, what to do when a suitable organ became available, alternatives to transplantation, and how the waiting list worked.240 242-245 Family members were afraid to bother the healthcare team 246, and perceiving little power in comparison to health professionals, downplayed their knowledge in front of them.210 Patients and carers were responsible of obtaining and carrying their medical files and test-results to appointments when the health-care administrative systems were not integrated.49 125 Some had anticipated that transplantation would offer dramatic health improvement but were disappointed when they experienced side effects, particularly cancer.44 63 101 106 122 167 190 193 199 206 214 247-251

*Social support*. Most people highlighted the support from family, neighbours, friends, staff, other patients and church communities; friends, staff and spiritual groups were particularly important for those living alone.39 44 60 62 215 247 249 252-258 A lack of social support was also frequently reported.44 60 247 259 In a UK study, patients socio-economic disadvantage adversely affected the availability of social support, and it was suggested that personal relationships sometimes broke down when potential donors declined to donate.39 Attending dialysis was sometimes seen as a social outlet, where they could make friends with staff and patients. Younger participants often considered the schedule flexibility of home dialysis as an opportunity for maintaining their employment and contact with their family and established social networks.61 152 To demonstrate resilience, some patients tried to maintain a sense of normalcy, integrating the dialysis community into their social network.42 139 210 260

**Experienced control**

*Personal control*. Feelings of personal control were achieved through learning how to manage CKD and ESKD, finding a balance between illness and normalcy, or even denying the seriousness of their condition.218 260 261 The experience of feelings of personal control led to increased self-confidence and well-being.15 189 251 Strategies for maintaining control included requesting tests, withholding information from clinicians, monitoring and modifying their treatments, and checking the activities of dialysis nurses assisting them.139 246 251 262-265 People with ESKD experimented with their therapy to determine if the prescriptions were really necessary, they also shortened dialysis hours to reduce worsening symptoms, to meet work commitments, or to participate in an unexpected social situation.54 55 Lengthening treatment hours could facilitate higher than usual fluid removal or managing symptoms.54 55 Some patients entrusted decisions entirely to the care team, and this promoted feelings of security.61 70 102 107 266 267 The main barrier to personal control was lack of information about treatments, test results, and the course of their illness and that they could not choose when and where to travel.15 43 61 63 197 239 268 However, even when patients knew they were not in control, they felt unsafe if the treatment went differently from what was expected.269 Patients recognised prognostic uncertainty, and their own fear of incompetence as an obstacle to choosing the appropriate dialysis modality.54 72 92 132 133 150 161 223 251 268 270-274 For many patients, home dialysis restored a sense of control and freedom to manage their schedule, especially if it was nocturnal.51 70 158 220 263 275 Dependence on emergency care or on fund-raising tasks to cover life-saving treatment represented a severe case of lack of experienced control.35 47-49 52 66

*Control and Decision-making.* Control translated into participation in decision-making; which was affected by the healthcare staff’s attitude toward the patients’ adherence to treatment.236 Lack of choice in decision-making about dialysis modality was very common; when possible, modality was negotiated and agreed after discussions with clinicians and family members, reading educational material, or attending informational meetings.202 248 270 273 274 276-278 Home dialysis patients appreciated training to build confidence and skills to utilise the machine.54 70 111 270 279 280 Patients in dialysis aspired to improve their situation by receiving a transplant, motivating them to adhere to treatment; other motivations included family, especially their children, work and beliefs.55 58 281 People with ESKD whose clinicians failed to discuss care, eligibility and ineligibility for transplant, and potential donors with them felt disempowered.39 55 57 58 77 78 169 282 When relatives offered to donate a kidney, many patients felt reluctant to accept this because of their concerns about the future health of the donor; other patients had reservations about accepting kidneys from deceased donors because of the donor’s age and medical history.172 181 235 Once transplanted, the main clinical objective was preserving the graft. However, the disease and its treatment continued to be a significant burden on patients’ social capital and financial capacity, with unexpected side effects.49 63 89 96 167 283-285

*Carers’ involvement*. Relatives wanted to be involved in discussions on dialysis modality as dialysis would take up a large part of their lives.55 70 111 156-158 223 279 286 Carers of patients on home dialysis needed to know more about the dialysis techniques to feel confident about self-managing the treatment, they stressed the importance of 24-hour telephone access for advice.61 69 Family members were afraid to bother the healthcare team246, and perceiving little power in comparison to health professionals, used strategies to downplay their knowledge of the disease or the treatment in front of them.210 287 To cope with caring, carers sought support in psychiatric help or religion when available, or support in religion.141 247 Patients who decided to stop dialysis did not usually ask for their carers’ opinion; when physicians thought the patient was too ill to decide, carers were consulted and felt death could be liberating if the patient was in pain and with no response to treatment.134 141 161

*End-of-life decisions*. Some patients felt that advance care planning (ACP) was hard and unnecessary as they trusted their families to make decisions; others were less concerned, trusted their healthcare team and felt empowered.236 288 289 Family members felt ACP was necessary as a means to protect patients.290-292 At the end-of-life, maintaining control was a struggle with respect to autonomy and dignity.134 136 205 251 Patients based their dialysis withdrawal or non-acceptance decision on having lived a full life, on nature taking its course, on their fear of being a burden for their families, their bodies being invaded and dialysis accelerating death.128 293 For some, the decision to withdraw from dialysis meant asserting their self-determination.251 294 Carers’ acceptance of patients’ decision was influenced by the perception of conservative management as a non-invasive treatment, the advanced age of the patient, and the lack of benefit received from haemodialysis.64 128 134 161 Although family members were often uncomfortable about making end-of-life decisions, they tended to recognise it was important to respect the patient´s wishes.202 233 292 Figure 2 shows thematic schema of experienced control and cognitive authority in CKD.

**DISCUSSION**

Our findings demonstrate that the work and capacity of patients and carers are highly unstable situational factors that make up the BoT. Capacity is particularly diminished by socioeconomic factors, which ultimately exacerbates the work of patients and their carers; this may occur even in regions with universal health coverage. Particularly in LMICs, patients with ESKD are often under-insured or not at all, which makes it almost impossible for them to attain life-saving treatments. Patients with ESKD can be caught in a vicious cycle whereby they lose their job and health insurance because of ill health or because they need time off from work to attend dialysis, leading to exacerbations in disease, lack of financial access to treatment, and difficulty obtaining a job because of poor health. Patients often fear catastrophic consequences due to a lack of financial capacity, and make strenuous efforts to prevent them. Thematic syntheses with robust methods have covered different aspects of being a patient with CKD.295-308 Here, we focused on three elements of BoT, namely workload, capacity and experienced control, to develop an understanding of the BoT of CKD, focusing on ESKD and including the experiences of patients in contexts of structural inequalities.

Worldwide, many individuals with CKD and especially with ESKD receive no treatment or receive only fragmented care.8 35 309-314 Millions of preventable deaths occur because of lack of access to RRT.9 Moreover, in some LMICs with universal health coverage, resources may be limited because of geography or poor infrastructure; in such cases, the use of free health providers can create delays that compromise the treatment itself, resulting in patients struggling to pay for private providers. When this occurs, healthcare becomes fragmented and uncoordinated. Even in some modern welfare states, health inequalities persist, particularly affecting minorities, those who are unemployed, or undocumented.315 One example is the use of emergency haemodialysis by undocumented and uninsured immigrants with ESKD.52 Several studies have highlighted the imperative necessity to address this disturbing reality.316-323

When health systems fail to meet patients’ treatment needs, patients mobilise resources and develop coping strategies such as accepting charity or selling assets.13 29 312 This distressing scenario adds to their workload and very easily overwhelms patients’ capacity. Transportation to and from dialysis centres is a frequent challenge, it is time-consuming, costly, or simply not available. Those patients living in non-urban areas in countries where home dialysis is not available have to travel long distances or relocate to access treatment; some may be faced with the decision of leaving their young children in the care of others for long periods of time. In many LMICs, the costs of RRT remain prohibited for both individuals and health-care systems; dialysis and transplantation costs often lead to financial ruin of the family, discontinuation, and death.324 In fact, patients, families, and health-care professionals are burdened with having to choose between life and death.324 On the other hand, in countries with robust health coverage, patients may feel overwhelmed even by having to travel short distances to the treatment centre every two days, especially if they do not have support or, if offered home dialysis, they may experience social isolation, unexpected costs, and lack of sufficient technical assistance. In settings in which renal replacement therapy (RRT) costs are covered, patients may have the choice of not initiating or withdrawing from dialysis.324 Among other factors, advanced age, white ethnicity, and chronic disease are associated with dialysis withdrawal.325

Support from social networks, professionals, and other patients is critical in improving patient’s capacity. Spirituality and church communities are significant resources for coping with illness and its treatment, as seen in several studies.21 201 249 257 326-329 However, social support is not guaranteed; in some cultures, patients perceive lack of support by their own networks caused by discrimination because of their illness, leading to intolerable levels of BoT.44 60 247 259 It has also been shown that informal care offered by family, friends or neighbours can burden patients through uncomfortable feelings of dependency or the obligation to have an optimistic attitude toward their condition.330 Our findings support this view; patients often fear becoming a burden on their families, which affects their decisions related to treatment options.

We confirmed that patients’ capacity can be undermined by insufficient or inadequate information. Deficits in communication between patients and professionals are endemic and rooted in structural and system factors.20 30 296 308 331 This shortfall affects decisions regarding dialysis modality, medication management, and the possibility of utilising a living donation. Patient discussions with professionals must result in a collaborative partnership and should not simply provide information.330 For example, patients’ concerns and expectations about waitlists, eligibility, and allocation for transplantation could be addressed via additional information, clinical conversations, and access to specialised psychological therapists.306

Immigrant populations do not always have access to healthcare; when they do, language, cultural, and religious differences can act as barriers to care and contribute to the BoT. In developed countries, the need to provide RRT for migrants and refugees with ESKD will increase as more people are displaced to countries where RRT is available; this situation poses ethical challenges at the societal and individual levels.321 It is necessary to promote and support equitable access to care for those living within any border by means of organisational position statements and focused research.322 For migrants with access to care, culturally competent navigator programmes could contribute to the improvement of healthcare disparities.332

Surprisingly, patients who undergo haemodialysis tend to perceive that staff underestimate their capacities.58 94 101 202-204 When healthcare professionals do not take into consideration patients’ knowledge or values, a diminished participation in self-care and relationally induced non-adherence can occur. Treatment plans should be discussed against an assessment of patient and caregiver capacity, as well as their material, social, and cognitive resources.28 333

Changes in treatment may be needed as CKD progresses to its later stages—symptom control may become the main treatment focus.10 11 Our results relate predominantly to the BoT of patients with ESKD, as most reports included in this systematic review have addressed the experiences of this group of patients. Indeed, a large proportion of patients with early-stage CKD are unaware of their diagnosis.334 In patients whose kidney function will not decline to a point necessitating RRT, the overall BoT may be related to a reduction of risk.10 11 In the later stages of CKD, symptom control may become the main treatment focus, and the time-consuming and invasive treatment of dialysis, by any modality, and all tasks related to dialysis represent considerable portions of the burden.10 11 Moreover, the BoT is influenced by patients’ financial resources, family support, and comorbidities, as well as the healthcare setting. In fact, because of the likely coexistence of multiple conditions, elderly patients experience a greater BoT than do younger patients.24 Management should be co-ordinated among professionals, particularly for patients with ESKD and multiple morbidities,23 who frequently experience fragmented care with a substantial time and travel burden, as well as contradictory healthcare advice.23

Challenged by constraints, a patient’s sense of control can become fragile. As seen in our review, patients often employ a range of strategies to retain their control, such as withholding clinical information from professionals, asking for additional tests, or modifying their treatment. Although a patient’s capacity to cope with BoT is often exceeded, healthcare systems increasingly delegate responsibilities to patients and carers, focusing on self-management and compliance.30 335 When overwhelmed, patients may be forced to renegotiate their responsibilities with actors in the health system and their own social networks.29

Our review has important limitations. The variety of methodologies, quality of reporting, and heterogeneity of perspectives make synthesis difficult. Only studies that included face-to-face interviews were included to capture rich qualitative data, and studies that reported methods such as telephone and postal questionnaires or surveys were excluded. Studies with paediatric patients and/or their carers were excluded, as BoT may significantly differ. Although the use of framework analysis can improve the transparency of coding and identify underlying assumptions, it can also be interpreted as a limitation because findings may be influenced by and connected to these theories. For a more global perspective, studies published in other languages could have been included. Grey literature was excluded to manage the scope of the review. We analysed data with a coding framework supported by middle-range theories to understand the work involved in being a person with CKD and how practises are organised and integrated into social contexts. The major strengths of this study are the comprehensive inclusion of publications in the English, Spanish, and Portuguese languages to understand the experience of patients in LMICs, which may enhance the transferability of our findings, the broad description of BoT across all stages of CKD, and the use of theories to underpin our findings. However, the included studies representing only some LMICs can hardly be presumed to reflect patients’ experiences in these countries.

**CONCLUSION**

To the best of our knowledge, this is the first theory-led review that focuses on the structural inequalities that shape patient and caregivers’ experiences related to BoT in CKD. The inclusion of LMICs extends our understanding of the experiences of individuals living in these countries and the work they undertake to manage their conditions. CKD can result in invasive and exhausting BoT, which is exacerbated in contexts of limited health coverage, socioeconomic disadvantages, and marked imbalances in power. An urgent, collaborative, multipronged approach is needed to address the overwhelming BoT of CKD that, in many populations, results in premature death.8 312 However, knowledge gaps persist in resource-limited settings and the nephrology community need to quantify the burden of CKD, understand its social impact, raise awareness of the disease among healthcare workers, and advocate for cost-effective and setting-specific detection and prevention strategies.9 324 336 337 The design of innovative policies, interventions, and activities are warranted to support and empower patients, considering the constraints and structure of systems that patients navigate in their disease trajectory. This will lead to a better understand of their burden, with the objective of improving quality of care and the illness experience.

**ABBREVIATIONS**

BoT, burden of treatment; CKD, chronic kidney disease; ESKD, end-stage kidney disease; LMIC, low- and middle-income countries.

**DECLARATIONS**

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**Availability of data and material**

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May CR, Cummings A, Myall M, Harvey J, Pope C, Griffiths P, Roderick P, Arber M, Boehmer K, Mair FS *et al*: **Experiences of long-term life-limiting conditions among patients and carers: what can we learn from a meta-review of systematic reviews of qualitative studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease?** *BMJ Open* 2016, **6**(10):e011694.

Search strategy is included as supplementary file.

**Competing interests**

The authors declare that they have no competing interests.

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**Authors’ contributions**

JR drafted the paper. AC, MM, CRM, JH screened titles and abstracts in first search round. Full papers were screened by JH, KL, MM, KH and AC. JR performed database searches for update and extension of search. JR, JPA and FC screened updated results. JR, CRM and JPA performed content analysis. CRM, MM, AC, JPA critically reviewed the manuscript for important intellectual content; all authors approved the final version of the paper.

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**Table 1. PICO criteria for including studies**

|  |  |
| --- | --- |
| **Population:** | Patients of at least 18 years of age, diagnosed with CKD, and formal and informal carers |
| **Intervention:** | Experiences of healthcare provision, any type of treatment for CKD. |
| **Comparator:** | Not limited to comparator studies; |
| **Outcomes:** | Qualitative data on patients and carers’ experiences of care for those patients with CKD. |
| **Study type:** | Primary studies, qualitative or mixed methods studies. |
| **Time:** | From 2000 to present. |

**Table 2:** Characteristics of included studies

| Author | Year | Country | Setting | Patients | Carers | Type of patient | Data collection | Data analysis reported |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Aasen107 | 2012 | Norway | 5 H, East, West. | 11 |  | ESKD | Interviews | Critical discourse |
| Aasen 246 | 2012 | Norway | 5 H, East, West |  | 7 | ESKD | Interviews | Critical discourse |
| Aasen 287 | 2012 | Norway | 5 H, East, West | 11 | 17 | ESKD | Interviews | Critical discourse |
| Al-Arabi 104 | 2006 | United States | 1 C, Southwest | 80 |  | ESKD | Interviews | Naturalistic inquiry, thematic |
| Allen 173 | 2011 | Canada | 1 H, urban | 7 |  | ESKD | Ethnographic observations, interviews | Participatory action, thematic |
| Allen 64 | 2015 | Canada | 2 H | 6 | 11 | ESKD | Ethnographic observations, interviews | Thematic |
| Anderson 77 | 2008 | Australia | 9 H, 17 C | 241 |  | ESKD | Interviews | Thematic |
| Anderson 53 | 2012 | Australia | 9 H, 17 C | 241 |  | ESKD | Interviews | Thematic |
| Arslan 200 | 2009 | Turkey | 1 H, Konya | 10 |  | ESKD | Interviews | Content |
| Ashby 38 | 2005 | Australia | 2 H, Melbourne | 16 |  | ESKD | Interviews | Grounded theory |
| Avril-Sephula 118 | 2014 | United Kingdom | 1 H, North | 8 |  | ESKD | Interviews | Thematic |
| Axelsson 187 | 2012 | Sweden | 2 H, 2 C | 8 |  | ESKD | Interviews | Phenomenological, hermeneutical |
| Axelsson 136 | 2012 | Sweden | 2 H, 2 C | 8 |  | ESKD | Interviews | Phenomenological, hermeneutical |
| Axelsson 134 | 2015 | Sweden | 2 H, 1 C, urban |  | 14 | ESKD | Interviews | Content |
| Bailey 235 | 2015 | United Kingdom | Bristol | 32 |  | Transplanted | Interviews | Constant comparison |
| Bailey 39 | 2016 | United Kingdom | Bristol | 13 |  | Transplanted | Interviews | Constant comparison |
| Baillie 156 | 2015 | United Kingdom | Wales | 16 | 9 | ESKD | Interviews | Thematic |
| Baillie 157 | 2015 | United Kingdom | Wales | 16 | 9 | ESKD | Interviews | Thematic |
| Barbosa 145 | 2009 | Brazil | 1 C, Rio de Janeiro | 10 |  | ESKD | Interviews | Grounded theory |
| Bath 252 | 2003 | United Kingdom | South | 10 |  | ESKD | Interviews | Phenomenological |
| Beanlands 210 | 2005 | Canada | Ontario |  | 37 | ESKD | Interviews | Grounded theory |
| Bennett 197 | 2013 | Australia | 4 C | 9 | 2 | ESKD | Interviews facilitated by images | Thematic |
| Blogg 69 | 2008 | Australia | urban |  | 5 | ESKD | Interviews | Ethnographic |
| Boaz175 | 2014 | United Kingdom | rural, urban | 25 |  | Transplanted | Interviews | Constant comparison |
| Bourbonnais 105 | 2012 | Canada | 1 H | 25 |  | ESKD | Interviews | Content |
| Bridger 238 | 2009 | United Kingdom | GP, South | 23 |  | CKD | Interviews, drawings, journals | Grounded theory |
| Bristowe 126 | 2015 | United Kingdom | 2 C, London | 20 |  | ESKD | Interviews | Thematic |
| Brito-Ashurst121 | 2011 | United Kingdom | London | 20 |  | CKD | Focus groups, vignettes and diaries | Thematic |
| Browne 226 | 2016 | United States | South | 40 |  | ESKD | Focus groups | Content |
| Buldukoglu186 | 2005 | Turkey | Antalya | 40 |  | Transplanted | Open ended questions | Constant comparison |
| Burnette 78 | 2009 | Australia | 1 C, Perth | 6 |  | ESKD | Interviews | Thematic |
| Cadena 154 | 2015 | Mexico | Coyotepec, Mexico | 5 |  | ESKD | Interviews | Interpretative phenomenological |
| Calvey 146 | 2011 | Ireland | NA | 7 |  | ESKD | Interviews | Colaizzi's method |
| Calvin 251 | 2004 | United States | 3 C, Texas | 12 |  | ESKD | Interviews | Constant comparison |
| Calvin 292 | 2014 | United States | Texas |  | 18 | ESKD | Interviews | Interpretative, Glaserian |
| Campos 234 | 2003 | Brazil | 1 H, Sao Paulo | 7 |  | ESKD | Interviews | Thematic |
| Campos 87 | 2010 | Brazil | 1 H, Sao Paulo | 7 |  | ESKD | Interviews | Thematic |
| Campos 88 | 2015 | Brazil | H, C, Paraná | 23 |  | ESKD | interviews | Content |
| Cases 279 | 2011 | United Kingdom | NA | 6 |  | ESKD | Interviews | Phenomenological |
| Cervantes 52 | 2017 | United States | 1 H, Colorado | 20 |  | ESKD | Interviews | Thematic |
| Chatrung 188 | 2015 | United States | California | 8 |  | CKD | Interviews | Thematic |
| Chenitz 86 | 2014 | United States | 4 C, Pennsylvania | 30 |  | ESKD | Interviews | Grounded theory |
| Chiaranai 40 | 2016 | Thailand | 1 H | 26 |  | ESKD | Interviews | Thematic |
| Cho 41 | 2016 | South Korea | 1 H, South | 5 |  | ESKD | Interviews | Colaizzi's method |
| Chong 164 | 2016 | South Korea | 1 H, South | 8 |  | ESKD | Interviews | Content |
| Clarkson 106 | 2010 | United States | Oklahoma | 10 |  | ESKD | Interviews | Thematic |
| Costa 198 | 2014 | Brazil | 3 H, Paraíba | 26 |  | ESKD | Interviews | Lexical |
| Costantini 92 | 2008 | Canada | Ontario | 14 |  | CKD | Interviews | Content |
| Cox 148 | 2016 | United States | 6 C, New Mexico | 50 |  | ESKD | Interviews | Interpretive description |
| Cramm 219 | 2015 | The Netherlands | 1 H, Rotterdam | 15 | 12 | ESKD | Interviews | Factor analysis, Q methodology |
| Cristóvao 113 | 2013 | Portugal | 1 C, Lisbon | 20 |  | ESKD | Interviews | Thematic |
| Crowley-Matoka83 | 2005 | Mexico | 2 prog, Guadalajara | 50 |  | Transplanted | Interviews | NA |
| Curtin 265 | 2001 | United States | Diverse | 18 |  | ESKD | Interviews | Content |
| Curtin 264 | 2002 | United States |  | 18 |  | ESKD | Interviews | Content |
| da Silva 103 | 2016 | Brazil | 1 C, Northeast | 30 |  | ESKD | Interviews | Content and thematic |
| da Silva 338 | 2011 | Brazil | 1 H, Rio Grande do Sul | 9 |  | ESKD | Interviews | Qualitative |
| Darrell 281 | 2016 | United States | 1 H | 12 |  | ESKD | Interviews | Giorgi's method |
| Davison 231 | 2006 | Canada | Alberta | 24 |  | ESKD | Interviews | Constant comparison, iterative |
| Davison 291 | 2006 | Canada | 1 H | 19 |  | ESKD | Interviews | inductive |
| de Brito 89 | 2015 | Brazil | 1 H, Minas Gerais | 50 |  | Transplanted | Interviews | Collective subject technique |
| de Rosenroll 277 | 2013 | Canada | 1 H |  | 10 | ESKD | Interviews | Constant comparison |
| Dekkers 42 | 2005 | The Netherlands | 2 C | 7 |  | ESKD | Interviews | Phenomenological |
| DePasquale 221 | 2013 | United States | NP, 1 C | 68 | 62 | CKD | Group interviews | Mixed method |
| dos Reis 155 | 2008 | Brazil | 1 H, Sao Paulo | 8 |  | ESKD | Interviews | Content |
| dos Santos 162 | 2011 | Brazil | Rio de Janeiro | 8 |  | ESKD | Interviews | Grounded theory |
| dos Santos 259 | 2015 | Brazil | 3 NP, Rio Grande do Sul | 20 |  | Transplanted | Interviews | Critical incident |
| Ekelund 43 | 2010 | Sweden | 1 C, South | 39 | 21 | ESKD | Interviews | Content |
| Erlang 203 | 2015 | Denmark | 1 H | 9 |  | CKD (Pre-dialysis) | Interviews | Systematic text condensation |
| Eslami 214 | 2016 | Iran | 4 C, Isfahan |  | 20 | ESKD | Interviews | Thematic |
| Finnegan-John90 | 2013 | United Kingdom | 1 trust, London | 118 | 12 | CKD/ESKD | Interviews and focus groups | Thematic |
| Flores 165 | 2004 | Brazil | 1 H, Rio Grande do Sul | 9 |  | ESKD | Interviews | Content |
| Fraguas 37 | 2008 | Brazil | 2 H, Minas Gerais |  | 18 | ESKD | Interviews | Content |
| Ghadami239 | 2012 | Iran | 1 charity, Isfahan | 15 |  | Transplanted | Interviews | Content |
| Giles 159 | 2003 | Canada | 1 H, urban | 4 |  | ESKD | Interviews | Thematic |
| Giles 160 | 2005 | Canada |  | 4 |  | ESKD | Interviews | Phenomenological |
| Goff 288 | 2015 | United States | New Mexico | 13 | 9 | ESKD | Interviews | Thematic |
| Goldane176 | 2011 | United States | 1 C | 39 |  | Transplanted | Focus groups and interviews | Iterative analysis |
| Gordon180 | 2007 | United States |  | 20 |  | Transplanted | Diary entries | Thematic |
| Gordon84 | 2009 | United States | 2 H, Illinois, New York | 82 |  | Transplanted | Interviews | Thematic |
| Gricio 114 | 2009 | Brazil | 1 H, Sao Paulo | 20 |  | ESKD | Interviews | Thematic |
| Gullick 339 | 2016 | Australia | 1 H, Sydney | 11 | 5 | ESKD | Interviews | Hermeneutic interpretation |
| Hagren 282 | 2001 | Sweden | 1 H | 15 |  | ESKD | Interviews | Content |
| Hagren 115 | 2005 | Sweden | 3 H | 41 |  | ESKD | Interviews | Content |
| Hain 189 | 2011 | United States | 6 C, Southeast | 56 |  | ESKD | Interviews | Story inquiry method |
| Hanson 70 | 2016 | Australia | 1 C, West | 20 |  | ESKD | Interviews | Thematic |
| Harrington 283 | 2016 | United Kingdom | 8 H | 24 |  | Transplanted | Interviews | Thematic |
| Harwood 270 | 2014 | Canada | 1 H | 13 |  | ESKD | Interviews | Content |
| Harwood 248 | 2005 | United Kingdom | 1 H, London | 11 |  | CKD/ESKD | Interviews | Content |
| Haspeslagh240 | 2013 | Belgium | 1 H, Leuven | 31 |  | Transplanted | Interviews and questionnaires | Thematic |
| Heiwe 137 | 2003 | Sweden | 1 H, Karolinska | 16 |  | ESKD | Interviews | Contextual |
| Heiwe 140 | 2004 | Sweden | 1 H, Karolinska | 16 |  | CKD/ESKD | Interviews | Contextual |
| Herbias 116 | 2016 | Chile | 1 C, Santiago | 12 |  | ESKD | Interviews | Streubert's method |
| Herlin 284 | 2010 | Sweden | 3 C | 9 |  | ESKD | Interviews | Giorgi's method |
| Hollingdale 227 | 2008 | United Kingdom |  | 20 |  | CKD/ESKD | Focus groups | Framework approach |
| Hong 120 | 2017 | Singapore | 1 H | 14 |  | ESKD | Interviews | Thematic |
| Horigan 138 | 2013 | United States | 1 C, Mid Atlantic | 14 |  | ESKD | Interviews | Content |
| Hutchison 290 | 2017 | Canada | 1 clinic, urban | 9 | 16 | CKD/ESKD | Interviews | Interpretive description |
| Iles-Smith 232 | 2005 | United Kingdom | 1 C, Manchester | 10 |  | CKD (Pre-dialysis) | Interviews | Thematic |
| Johnston 128 | 2012 | United Kingdom | 1 trust, London | 9 |  | ESKD | Interviews | Thematic |
| Kaba 340 | 2007 | Greece | 2 H, Athens | 23 |  | ESKD | Interviews | Qualitative |
| Kahn 35 | 2015 | United States | 2 NP, New York | 34 |  | CKD | Interviews | Thematic |
| Karamanidou 15 | 2014 | United Kingdom | 1 C, London | 7 |  | ESKD | Interviews | Interpretative, phenomenologic |
| Kazley 44 | 2015 | United States | 1 C, Southeast | 20 |  | CKD/ESKD | focus groups | Thematic |
| Keeping 73 | 2001 | Canada | East | 8 |  | ESKD | Interviews | Thematic |
| Kierans 167 | 2001 | Ireland |  | 5 |  | ESKD | Interviews, life stories | Phenomenological |
| Kierans 166 | 2005 | Ireland |  | 5 |  | CKD/ESKD | Interviews | Phenomenological |
| Kierans125 | 2013 | Mexico | 1 H, Jalisco | 51 | 87 | CKD/ESKD, transplanted | Interviews, observation \* | Ethnographic approach |
| King 91 | 2002 | United Kingdom | 1 C | 22 |  | CKD/ESKD | Interviews | Template approach |
| Knihs 168 | 2013 | Brazil | 1 C, South | 20 |  | ESKD | Interviews | Content |
| Krespi-Boothby147 | 2004 | United Kingdom | 1 H, 4 C | 16 |  | ESKD | Interviews | Thematic |
| Krespi-Boothby151 | 2013 | United Kingdom | 1 H, 4 C | 16 |  | ESKD | Interviews | Template approach |
| Ladin 202 | 2016 | United States | 2 C, Massachusetts | 23 |  | ESKD | Interviews | Thematic |
| Ladin 269 | 2017 | United States | 2 C, Massachusetts | 31 |  | ESKD | Interviews | Thematic Nutbeam’s framework |
| Landreneau 274 | 2006 | United States | 1 C, 1 NP, South | 6 |  | ESKD | Interviews | Colaizzi's method |
| Landreneau278 | 2007 | United States | 2 C, South | 12 |  | ESKD | Interviews | Colaizzi's method |
| Lawrence 169 | 2013 | United Kingdom | 1 C | 10 |  | ESKD | Interviews | Conceptual and categorical |
| Lederer 266 | 2015 | United States | 1 C | 32 |  | CKD/ESKD | Interviews | Thematic |
| Lee 223 | 2008 | Denmark | Diverse | 27 | 18 | ESKD | Focus groups | Thematic |
| Lee 45 | 2016 | Singapore | 1 organisation |  | 20 | ESKD | Interviews | Thematic |
| Lenci 256 | 2012 | United States |  | 4 |  | ESKD | Interviews | Thematic |
| Leung181 | 2007 | Hong Kong | 1 C | 12 |  | Transplanted | Interviews | Content |
| Lewis 285 | 2015 | United Kingdom | 14 H | 40 |  | ESKD | Interviews | Grounded theory |
| Lin 190 | 2015 | Taiwan | 1 C, S, rural | 15 |  | ESKD | Interviews | Constant comparison |
| Lindberg 46 | 2008 | Sweden | 1 C, mid country | 10 |  | ESKD | Interviews | Content |
| Lindberg 262 | 2013 | Sweden | 1 C, mid country | 10 |  | ESKD | Interviews | Content |
| Lindsay 280 | 2014 | Australia | 1 C, Sydney | 7 |  | ESKD | Interviews | Thematic |
| Llewellyn 271 | 2014 | United Kingdom | 4 C, London | 19 |  | ESKD | Interviews | Thematic |
| Lo 129 | 2016 | Australia | 4 H, Melbourne, Sydney | 58 |  | CKD/ESKD | Interviews and focus groups | Thematic |
| Lopes 170 | 2014 | Brazil | 1 C, Santa Catarina | 12 |  | ESKD | Interviews | Interpretative |
| Lopez-Vargas94 | 2014 | Australia | 3 C, New South Wales | 38 |  | CKD | Focus groups | Thematic |
| Lopez-Vargas 93 | 2016 | Australia | 3 C, New South Wales | 38 |  | CKD/ESKD | Focus groups | Thematic |
| Lovink 217 | 2015 | The Netherlands | 1 C | 12 |  | ESKD | Interviews | Content |
| Low 161 | 2014 | United Kingdom | 5 C, Southeast |  | 26 | ESKD | Interviews | Thematic |
| Machado 149 | 2003 | Brazil | Sao Paulo | 18 |  | ESKD | Interviews | Discourse |
| Marques 228 | 2014 | Brazil | Paraná |  | 10 | ESKD | Interviews | Content |
| Martin-McDonald194 | 2003 | Australia | 5 C | 10 |  | ESKD | Interviews | Thematic |
| Martin-McDonald 195 | 2003 | Australia | 1 C | 10 |  | ESKD | Interviews | Thematic |
| Mason 95 | 2007 | United Kingdom | 1 C | 9 | 5 | CKD | Focus groups | Framework approach |
| McCarthy 163 | 2010 | Australia | 1 H | 5 |  | ESKD | Interviews | Sequential |
| McKillop 267 | 2013 | United Kingdom | Clinics | 10 |  | CKD | Interviews | Thematic |
| Mercado-Martínez 49 | 2014 | Mexico | Jalisco, San Luis Potosí | 21 |  | Transplanted | Interviews | Thematic |
| Mercado-Martínez48 | 2015 | Brazil | 1 H, South | 11 | 5 | ESKD | Interviews | Content |
| Mercado-Martínez 47 | 2015 | Mexico | Public H and institutions, Jalisco | 37 | 50 | ESKD | Interviews | Content |
| Mitchell 205 | 2009 | United Kingdom | 1 C | 10 |  | CKD/ESKD | Interviews | Content |
| Molzahn 294 | 2012 | Canada | middle size city | 14 |  | CKD | Interviews | Thematic |
| Moran 204 | 2009 | Ireland | 1 H | 16 |  | ESKD | Interviews | Interpretive |
| Moran 150 | 2009 | Ireland | 1 H | 16 |  | ESKD | Interviews | Interpretive |
| Moran 133 | 2011 | Ireland | H | 16 |  | ESKD | Interviews | Interpretative |
| Morton 79 | 2010 | Australia | diverse | 95 |  | ESKD | Interviews | Thematic |
| Muduma 96 | 2016 | United Kingdom | 2 C | 37 |  | Transplanted | Focus groups | Qualitative |
| Nagpal 218 | 2017 | United States | 1 C, New York | 36 |  | ESKD | Interviews | Coding |
| Namiki 220 | 2010 | Australia | 1 H | 4 |  | ESKD | Interviews | Thematic |
| Niu 196 | 2017 | China | 1 C, Jiangsu | 23 |  | ESKD | Interviews | Continuous comparison |
| Nobahar 67 | 2016 | Iran | 1 H, Semnan | 8 | 12 | ESKD | Interviews | Graneheim Lundman Content |
| Nobahar 68 | 2016 | Iran | 1 H, Semnan | 8 | 12 | ESKD | Interviews | Granheim and Lundman's approach |
| Noble293 | 2009 | United Kingdom | 1 service, London | 30 | 17 | ESKD | Interviews | Constant comparison |
| Noble98 | 2010 | United Kingdom | 1 service, London | 30 | 17 | ESKD | Interviews | Constant comparison |
| Noble97 | 2012 | United Kingdom | 1 service |  | 19 | ESKD | Interviews | Constant comparison |
| Nygardh289 | 2011 | Sweden | 1 C, South |  | 12 | CKD (Pre-dialysis) | Interviews | Content |
| Nygardh236 | 2011 | Sweden | 1 C, South | 20 |  | CKD | Interviews | Latent Content |
| Malheiro Oliveira209 | 2012 | Brazil | Bahia | 19 |  | ESKD | Interviews | Categorical |
| Orr182 | 2007 | United Kingdom | 1 C | 26 |  | Transplanted | Focus groups | Thematic |
| Orr183 | 2007 | United Kingdom | 1 C | 26 |  | Transplanted | Focus groups | Thematic |
| Oyegbile 65 | 2016 | Nigeria | 2 H, Southwest |  | 15 | ESKD | Interviews | Content |
| Pelletier-Hibbert 286 | 2001 | Canada | East |  | 41 | ESKD | Focus groups | Thematic |
| Piccoli 224 | 2010 | Italy | 1 H | 12 |  | CKD/ESKD, transplanted | Focus groups | Not clear |
| Pietrovski 208 | 2006 | Brazil | 1 H, Paraná | 15 |  | ESKD | Interviews | Content |
| Pilger 225 | 2010 | Brazil | 1 C, Paraná | 22 |  | ESKD | Interviews | Thematic |
| Polaschek 54 | 2003 | New Zealand | 1 C | 6 |  | ESKD | Interviews | Thematic |
| Polaschek 55 | 2006 | New Zealand | 1 regional department | 20 |  | ESKD | Interviews | Thematic |
| Polaschek 56 | 2007 | New Zealand | 1 regional department | 20 |  | ESKD | Interviews | Thematic |
| Prieto 130 | 2011 | Spain | Andalusia | 22 |  | ESKD | Interviews | Discourse |
| Rabiei 141 | 2015 | Iran | Isfaham |  | 20 | ESKD | Interviews | Thematic |
| Ravenscroft 260 | 2005 | Canada | 3 C | 7 |  | ESKD | Interviews | Inductive |
| Reid 268 | 2012 | United Kingdom | 1 C, clinics | 11 |  | CKD/ESKD | Interviews | Thematic |
| Reta 131 | 2014 | Spain | 1 H, Araba | 14 |  | ESKD | Interviews | Content |
| Richard 108 | 2010 | United States |  | 14 |  | ESKD | Interviews | Cultural negotiation model framework |
| Rifkin 99 | 2010 | United States | 1 C | 20 |  | CKD/ESKD | Interviews | Thematic |
| Rix 58 | 2014 | Australia | New South Wales, rural | 18 |  | ESKD | Interviews | Thematic |
| Rix 57 | 2015 | Australia | New South Wales, rural | 18 | 29 | ESKD | Interviews | Thematic |
| Rodrigues 191 | 2011 | Brazil | 1 C, South | 8 |  | ESKD | Interviews | Categorical |
| Ros244 | 2012 | United States | 1 H, Maryland | 19 |  | ESKD | Focus groups | Thematic |
| Roso 119 | 2013 | Brazil | 1 H, South | 15 |  | ESKD | Narrative interviews | Thematic |
| Russ 229 | 2005 | United States | 2 C, California | 43 |  | ESKD | Interviews | Anthropologic study |
| Russell241 | 2003 | United States | 1 C, Midwest | 16 |  | Transplanted | Interviews | Constant comparison |
| Rygh 71 | 2012 | Norway | North | 11 |  | ESKD | Interviews | Inductive, actor's point of view |
| Sadala 72 | 2012 | Brazil | 1 H | 19 |  | ESKD | Narrative interviews | Phenomenological, hermeneutical |
| Sahaf 222 | 2017 | Iran | 2 H, Sari | 9 |  | ESKD | Interviews | Van Manem Thematic |
| Salvalaggio 82 | 2003 | Canada | 1 H, Ontario | 12 |  | ESKD | Interviews | Immersion/crystalization |
| Schell 272 | 2012 | United States | 1 university system, 1 NP, North Carolina | 29 | 11 | CKD/ESKD | Interviews and focus groups | Thematic |
| Schipper184 | 2014 | The Netherlands | 5 H | 30 |  | Transplanted | Focus groups and interviews | Thematic |
| Schmid-Mohler85 | 2014 | Switzerland | 1 H, Zurich | 12 |  | Transplanted | Interviews | Content |
| Schober 206 | 2016 | United States | 14 States | 48 |  | ESKD | Interviews | Thematic |
| Seah 50 | 2013 | Singapore | 3 H | 9 |  | ESKD | Interviews | Interpretative phenomenological |
| Shahgholian 142 | 2015 | Iran | 1 H, Isfahan | 17 |  | ESKD | Interviews | Colaizzi's method |
| Shaw 275 | 2015 | New Zealand | diverse | 24 |  | ESKD | Interviews | Phenomenological |
| Sheu245 | 2012 | United States | Maryland | 27 | 23 | ESKD | Focus groups | Thematic |
| Shih 59 | 2011 | New Zealand | 1 C, North | 7 |  | ESKD | Interviews | Hermeneutical and thematic |
| Shirazian 123 | 2016 | United States | 1 C, Northeast | 23 |  | CKD | focus groups | Thematic |
| Sieverdes 174 | 2015 | United States | 1 C, South Carolina | 27 |  | Transplanted | focus groups | Thematic |
| Smith 207 | 2010 | United States | 2 C | 19 |  | ESKD | focus groups | Content |
| Spiers177 | 2015 | United Kingdom | 1 C, London | 4 |  | Transplanted | Interviews | Interpretative phenomenological |
| Spiers 171 | 2016 | United Kingdom | 2 online groups | 10 |  | ESKD | Interviews | Thematic |
| Stanfill178 | 2012 | United States | 1 C, mid-South | 7 |  | Transplanted | Focus groups | Iterative |
| Stewart 81 | 2012 | United States | 2 C, urban | 19 |  | ESKD | Interviews | Coding |
| Tanyi201 | 2006 | United States | Mid-West | 16 |  | ESKD | Interviews | Colaizzi's method |
| Tanyi 192 | 2008 | United States | 2 C, mid-West | 16 |  | ESKD | Interviews | Colaizzi's method |
| Tanyi 193 | 2008 | United States | Mid-West | 16 |  | ESKD | Interviews | Colaizzi's method |
| Tavares 216 | 2016 | Brazil | 1 H, Rio de Janeiro |  | 19 | ESKD | Interviews and groups | Content |
| Taylor 111 | 2016 | Australia | 2 H, Sydney | 26 |  | ESKD | Interviews | Thematic |
| Taylor 215 | 2015 | United Kingdom | 6 trusts | 15 | 11 | ESKD | Interviews | Constant comparison |
| Theofilou 122 | 2013 | Greece | 1 H, Athens | 10 |  | ESKD | Interviews | Phenomenological |
| Thomé 247 | 2011 | Brazil | 1 H, Rio Grande do Sul |  | 10 | ESKD | Interviews | Cultural |
| Tielen179 | 2011 | The Netherlands | 1 C | 26 |  | Transplanted | Interviews | Q methodology |
| Tijerina 76 | 2006 | United States | 8 C, Texas | 26 |  | ESKD | Interviews | Coding |
| Tong63 | 2009 | Australia | 4 H, Brisbane, Sydney, Melbourne | 63 |  | CKD/ESKD | Focus groups | Thematic |
| Tong152 | 2013 | Italy | 4 C, Bari, Marsala, Nissoria, Taranto | 22 | 20 | ESKD | Interviews | Thematic |
| Tong 237 | 2015 | Australia | 1 C, Adelaide | 15 |  | CKD/ESKD | Interviews | Thematic |
| Tonkin-Crine 127 | 2015 | United Kingdom | 9 C | 42 |  | ESKD | Interviews | Thematic |
| Torchi 153 | 2014 | Brazil | 1 C, Rio de Janeiro | 10 |  | ESKD | Interviews | Collective subject technique |
| Tovazzi 117 | 2012 | Italy | North | 12 |  | ESKD | Interviews | Phenomenological |
| Tweed 109 | 2005 | United Kingdom | 1 C, Leicester | 9 |  | ESKD | Interviews | Phenomenological |
| Urstad242 | 2012 | Norway | 1 C | 15 |  | Transplanted | Interviews | Hermeneutic |
| Valsaraj 60 | 2014 | India | 1 H, South Karnataka | 10 |  | ESKD | Interviews | Phenomenological |
| Velez 100 | 2006 | Spain | 1 C | 12 |  | ESKD | Interviews | Thematic |
| Vestman 263 | 2014 | Sweden | 1 H | 9 |  | ESKD | Written narratives | Thematic |
| Visser 276 | 2009 | The Netherlands | 1 C | 14 |  | ESKD | Interviews | Thematic |
| Wachterman 172 | 2015 | United States | 1 C | 16 |  | ESKD | Interviews | Thematic |
| Walker 124 | 2012 | United Kingdom | 1 H | 9 |  | CKD | Interviews | Thematic |
| Walker 51 | 2016 | New Zealand | 3 C | 43 | 9 | ESKD | Interviews | Thematic |
| Walker 61 | 2016 | New Zealand | 3 C | 43 | 9 | ESKD | Interviews | Thematic |
| Walker 80 | 2017 | New Zealand | 3 C | 13 |  | ESKD | Interviews | Thematic |
| Walton 258 | 2002 | United States | 1 H, rural, Northwest | 11 |  | ESKD | Interviews | Grounded theory |
| Walton 257 | 2007 | United States | 1 C | 21 |  | ESKD | Interviews | Grounded theory |
| Weil 253 | 2000 | United States | 2 C, rural, Northwest | 14 |  | ESKD | Interviews | Thematic |
| Wells 254 | 2015 | United States | 3 C, 1 NP, Texas | 17 | 17 | ESKD | Interviews | Thematic |
| Wells 62 | 2015 | United States | 3 C, 1 NP, Texas | 15 | 21 | ESKD | Interviews | Thematic |
| White 139 | 2004 | United States | 1 C, Colorado | 6 | 9 | ESKD | Interviews | Thematic |
| Wiederhold185 | 2012 | Germany | 1 C | 10 |  | Transplanted | Interviews | Content |
| Wilkinson 75 | 2011 | United Kingdom | Luton, West London, Leicester | 48 |  | ESKD | Interviews | Thematic |
| Wilkinson 233 | 2014 | United Kingdom | 4 C | 16 | 45 | Transplanted | Interviews and focus groups | Thematic |
| Wilkinson 74 | 2016 | United Kingdom | 4 C | 16 | 45 | ESKD | Interviews and focus groups | Thematic |
| Williams 101 | 2009 | Australia | 2 H | 20 |  | CKD | Interviews | Qualitative |
| Williams 102 | 2008 | Australia | 2 H, Melbourne | 23 |  | CKD | Interviews and focus groups | Interpretative |
| Williams 261 | 2009 | Australia | 1 H, Melbourne | 23 |  | CKD | Interviews | Qualitative |
| Wilson 255 | 2015 | United Kingdom | 3 C | 15 | 15 | ESKD | Focus groups | Thematic |
| Winterbottom 230 | 2012 | United Kingdom | 1 C, Northern England | 20 |  | CKD | Interviews | Thematic |
| Wu 66 | 2015 | Taiwan | 2 C, Central | 15 |  | ESKD | Interviews | Thematic |
| Xi 110 | 2011 | Canada | 1 C, Ontario | 13 |  | ESKD | Interviews | Thematic |
| Xi 158 | 2013 | Canada | 1 C, Ontario | 10 |  | ESKD | Interviews | Thematic |
| Yeun 143 | 2016 | South Korea | 1 H, Seoul |  | 33 | ESKD | Interviews | Q methodology |
| Yngman-Uhlin 135 | 2010 | Sweden | Southeast | 14 |  | ESKD | Interviews | Phenomenological |
| Yngman-Uhlin132 | 2016 | Sweden | 1 H, Southeast | 8 |  | ESKD | Interviews | Content |
| Yodchai 249 | 2016 | Thailand | 2 H, Songkhla | 20 |  | ESKD | Interviews | Qualitative |
| Yodchai199 | 2012 | Thailand | 1 C, South | 5 |  | ESKD | Interviews | Grounded Theory |
| Yu 112 | 2014 | Singapore | NKF | 32 |  | ESKD | Interviews | Thematic |
| Yumang 144 | 2009 | Canada | 1 H, Quebec | 9 |  | ESKD | Interviews | Colaizzi's method |
| Ziegert 213 | 2001 | Sweden |  |  | 12 | ESKD | Interviews | Pragmatic approach |
| Ziegert 211 | 2006 | Sweden | Southwest |  | 13 | ESKD | Interviews | Content |
| Ziegert 212 | 2009 | Sweden | Southwest |  | 20 | ESKD | Interviews | Content |

**Table 3. Illustrative quotations**

|  |
| --- |
| **Structural inequalities** |
| [Undocumented immigrant in US without access to scheduled haemodialysis] When you enter through the emergency department, you arrive in bad shape...you need to have a high potassium or they send you home even though you feel you are dying. Sometimes, you crawl out when they decide to not do dialysis. You eat a banana because it is high in potassium even though you may die and you go back and wait and hope that they will do dialysis so that you don’t feel like you are drowning and so that the anxiety goes away. (American patient).52  My mother got some help from DIF (Mexican social assistance office), it was five haemodialysis sessions; when there was no session left, we went to a private centre, there is a foundation there and they helped us... they gave me eight sessions. After that, my mom went to DIF in Zapopan again and they sent us to DIF in Guadalajara. We got some help there (Mexican patient without coverage).47 |
| **Workload** |
| Sometimes I have to sit and wait at least an hour and I have to call and say my ride is not here yet, which makes me late getting there, which makes me late getting on the machine, which makes me late getting off the machine. And then… coming to pick you up, if you’re not ready when they get there, they will leave you and you’ll have to sit and wait and wait and wait (American patient).86  It is always in the back of your mind that it [the transplant] will fail, at times. And I think if anything that makes you more inclined to comply with your treatment, comply with your medication because at the end of the day if, you know, if you do the utmost that you can and you take your medicine and you go to your follow up appointments, then there’s hopefully less chance of it failing in the long run. (Woman, 3 years+ post- transplant).175  I suppose mine being genetic. It’s been very difficult to find what kind of diet you’re supposed to follow. You read one bit of information and it tells you this and you read another bit and it tells you don’t eat that, which the other one said you must eat. there’s no clear guideline on what it is you can or can’t eat. (Man, 38 years, CKD stage 3).94  It was a lot more work because of all the things that you had to learn... I don’t eat out anymore... It’s tough taking so many pills (Patient with CKD).92 |
| **Capacity** |
| Before she left (pause) when everything was happy and happy sort of thing, you know, I think it was- she was going to give a kidney to somebody else and somebody else was going to give a kidney to somebody and somebody was going to give a kidney to me – like a triangle... she was willing to do that. It didn’t happen, um (pause) ‘cos she left (UK patient).39  it’s a kind of tiredness that you wouldn’t wish on your worst enemy ... when you can’t read, you’re too tired to watch the telly, you’re too tired to do anything, because your brain is so tired like all of you ... it feels like you’re kind of hollow inside ... like it’s only a kind of shell that’s functioning.137  Well about five years ago, I went to the hospital because I wasn’t feeling good and they took my blood pressure and it was 200 over something.....Then while they were trying to get my blood pressure down, they said something about my kidneys. And I didn’t know the connection between high blood pressure and kidneys. (Evan, African American male, 50, CKD Stage 3).35  It wasn’t till about 2 years ago, until I fully understood and I’ve had the kidney disease from the age of 15, what exactly my [kidney] function was and I got a fright. No one had ever told me.’ (Man, 38 years, CKD stage 3).94 |
| **Control and decision making** |
| I have free reign of whatever days I want to take off. They don’t tell me when I have to dialyse or when I can’t dialyse. Everything is under my control. That’s what I like (talking on home dialysis, patient from Canada).158  If I’m going to feel this bad for the rest of my life, do I just want to end it now? (Woman, 40s, CKD stage 4).63 |
| **Carers’ involvement** |
| I just sit here like a robot. Nurses asked me to buy items that my mother needed. They never told me why she needed them. They ordered me to pay for dialysis, laboratory investigations and other things. I don't like it when I do not know the reason behind my actions. I am sad to see myself as a fool being tossed around (Caregiver from Nigeria).65 |
| **End-of-life** |
| Then [the home care nurse] said ‘Well you haven’t got to go on. We’ll make it quite peaceful for you to pass on.’ They can tell you, but it’s your body. It’s up to me to decide what I want to do’ (Patient from UK).205  I have heard [about] a lot of people that died on dialysis and had strokes on dialysis . . . Once I sit down there, I don’t know whether I’m gonna come out alive or dead. (Berta, age 45, blind amputee, dialysis patient for 18 months).76  "I think about [death] everyday. I mean you can't help it. I know that it is a terminal illness and it's not going to get better and that there is only one way out.(Wife of a Canadian patient on peritoneal dialysis).286 |

**Table 4: Summary of results**

|  |  |  |  |
| --- | --- | --- | --- |
| Qualitative Analysis | | |  |
| **Primary category** | **Secondary category** | **Summary results** | |
| **Structural disadvantage** | *Access to care*. | Socio-economic status is central to experience of CKD.35 37-63 125.  Treatment costs were major obstacle to care 47-49 64 125 as was limited access to healthcare for the un- or under-insured.35 40 48 50 52 60 67 68  Transplants, dialysis and drug treatments were often beyond the reach of low-income patients.35 47-49 66 83-85 125  Un- or under-insured people experienced increased dependence on emergency care.35 47-49 52 66  Poorly funded or unfunded healthcare was often fragmented and of indeterminate duration.47 48 64  For non-native speakers, language was an important barrier for having a discussion with care providers.53 74-76  Patients were often poorly informed about disease progression and treatment options.38 50 57 58 63 64 125 127-129 188 205 219-222 | |
| *Housing* | Homelessness, unsuitable housing, lack of utilities (electricity, clean running water) are critical to self-care and home dialysis.51 61 70 86 | |
| *Employment status*. | Loss of employment may lead to un- or under-insurance that limits or prevents access to treatment.35 39 45 52 60 69 72 87-91 | |
| **Workload** | *Self-care*. | Complex medication regimens were managed through dispensing aids, associated activities, family support.40 46 71 86 92-103  When taking care of their vascular access, patients made efforts to protect the arm.108 111  Patients controlled their diets and fluid intake, and managed food cravings and thirst.63 112  Many modified social activities to minimise exposure to hot weather, temptation, and social pressure.112 118-120  Women could face family conflicts if they followed prescribed diets.45 62 121-124  Restrictive diets were sometimes stigmatized as a sign of poverty.121 | |
|  | *Navigating health care structures.* | When pathways in system were not established, patients and carers had to identify institutions to obtain treatment and laboratory results.48 49 125 161  In settings with healthcare coverage, socio-economically disadvantaged patients found it difficult to access financial support.51  Lack of continuity of care contributed to patients using services without sufficient expertise in CKD.49 101  The efficiency focus of medical system was perceived as a barrier to a personal connection.173 102 | |
|  | *Negotiating costs and fund-raising.* | Fund-raising was important for those who were un- or under-insured, sold goods or services, organised raffles, or obtained loans.47-49 125  Patients contacted centres, other patients, and organisations to ask for free treatment when they were un – or under-insured.47 49 52 125 217 218 | |
|  | *Travel and time management.* | Patients often travelled for long distances to dialysis centres, 3 times a week.15 47-49 53 76 86 126-133  Home dialysis patients had to pay transport to training, appointments, and other check-ups.53 61 69-72  Patients arranged daily activities between sessions, adjusted activities to their fatigue, and tried to schedule medical appointments all on one day.55 134-145  Parents arranged child-care while they were in sessions or when they were tired.49 53 55 154 155 | |
|  | *Home dialysis.* | Training was required with extended periods off work.61 70 156-158  Homes needed physical adaptation, carers invested efforts in maintaining cleanliness and hygiene.152 158-162  Specific tasks were managing treatment at set times, recording blood pressure and body weight, titrating medications, adopting aseptic techniques.156 157 163 | |
|  | *Pre-transplant adaptation.* | Patients adjusted to being on transplant waiting-list, prepared for transplant from a deceased donor at any time.43 115 133 164-170  Specific adjustment tasks included: hospital visits, tests, and organizing payment for treatment.132 133 164 165 170-173  Some people needed to negotiate donation of a kidney by living relatives or others.39 47 164 174 | |
|  | *Post-transplant adjustment.* | Transplanted patients managed complex medication regimens, balanced against the need to re-enter the labour market to pay off loans.84 85 175-180  Post-transplant, patients needed to manage relationships, finances, and family responsibilities in context of prognostic uncertainty83 85 175-177 181-186 | |
| **Capacity** | *Physical and mental capacity* | Daily activities were limited by symptoms associated with dialysis (pain, fatigue, anxiety, and depression).37 44 55 63 90 96 138 140 154 187-199 Symptoms were sometimes overlooked by health professionals.58 94 101 202-204  When in poor health, patients relied on wider networks for food preparation, transportation, shopping, ordering supplies, symptom management, and training.37 118 161 205-208  Carers were involved in the treatment, accompanying patients to dialysis and responding to psychosocial needs.45 69 97 129 141 143 161 210-215 | |
|  | *Managing Information.* | Information on disease and treatment was often insufficient or difficult to comprehend, particularly during early stages.61 77 92 109 121 130 131 223-227 Short clinic visits, jargon, and anxiety were barriers to accessing information.61 102 223 231-234  For organ donation and transplantation, patients relied on information from other patients, health professionals, social workers, financial representatives, meetings and the internet.117 174 235-238  Information about the effects and side-effects of immunosuppression was important but hard to come by.178 184 185 239-242  Stress and urgency affected how people with CKD processed information provided by healthcare professionals.240 242-245 | |
|  | *Social support*. | Support from friends, family, neighbours, health professionals and other patients was essential.39 44 60 62 215 247 252-256 Lack of social support was a frequently reported problem.44 60 247 259  Patients ought to maintain a sense of normalcy, integrating dialysis community into their network.42 139 210 260  Younger patients sometimes considered home dialysis as an opportunity for employment and contact with social networks.61 152 | |
| **Experienced control** | *Personal control* *and decision-making* | When clinicians failed to discuss care, eligibility for transplant, and potential donors, patients felt disempowered.39 55 57 58 77 78 169 282  When relatives offered to donate a kidney, many patients were reluctant to accept because of concerns on future health of donor; other patients had reservations about kidneys from deceased donors because of the donor’s age, medical history.172 181 235  Once transplanted, main clinical objective was preserving the graft.49 63 89 96 167 283-285 | |
| *Carers’ involvement*. | Carers needed more information on dialysis techniques to feel confident, stressed the importance of 24-hour telephone support, wanted to be involved in decision-making as dialysis would also affect them.55 70 111 156-158 223 279 286  When carers perceived patient was in pain with no response to treatment, they sometimes yearned for the patient´s freedom of this condition through a peaceful death.134 141 161 | |
| *End-of-life decisions.* | Patients and carers emphasised self-determination, autonomy and dignity.134 136 205 251 294  End-of-life decisions were influenced by ideas about personal fulfilment, nature taking its course, fears of dependence, or of dialysis accelerating death.128 293 Decisions often passed to trusted carers or professionals.290-292  Acceptance of decisions was influenced by treatment modality, patient age, and ineffectiveness of haemodialysis.64 128 134 161  Families emphasized importance of respecting patients’ wishes.202 233 292 | |
|  |  | |

**Table 5. Main challenges related to burden of treatment**

| **Challenge** | **Group of patient mostly affected** | **Type of country mostly affected** | **Severity** |
| --- | --- | --- | --- |
| Limited access to healthcare for the un- or under-insured. | CKD, ESKD | LMIC | +++ |
| Dialysis, transplant surgery, immunosuppressive drugs were often beyond the reach of low-income patients. | ESKD | LMIC | +++ |
| Healthcare was often fragmented and of indeterminate duration for the un- or under-insured. | CKD, ESKD | LMIC | +++ |
| In settings with healthcare coverage, socially disadvantaged patients found it difficult to access financial support | CKD, ESKD | HIC | ++ |
| Fund-raising was important for those who were un- or under-insured | ESKD | LMIC | +++ |
| For non-native speakers, language was an important barrier for having a discussion with care providers. | CKD, ESKD | LMIC, HIC | ++ |
| Patients were often poorly informed about disease progression and treatment options. | CKD, ESKD | LMIC, HIC | ++ |
| Patients and carers had to identify institutions to obtain diagnosis, laboratory results, and treatment. | CKD, ESKD | LMIC | ++ |
| Homelessness, unsuitable housing, lack of utilities, critical to self-care and home dialysis. | ESKD | HIC, LMIC | ++ |
| Loss of employment may lead to un- or under-insurance limiting or preventing access to treatment. | ESKD | HIC, LMIC | +++ |
| Complex medication regimens were managed through dispensing aids, associated activities, family support. | CKD, ESKD | HIC, LMIC | + |
| When taking care of their vascular access, patients made efforts to protect the arm. | ESKD | HIC, LMIC | + |
| Patients controlled diets and fluid intake, modified social activities to minimise exposure and pressure. | CKD, ESKD | HIC, LMIC | ++ |
| Patients often travelled for long distances to dialysis centres, 3 times a week. | ESKD | HIC, LMIC | ++ |
| Home dialysis patients had to pay transport to training, appointments, and other check-ups. | ESKD | HIC, LMIC | ++ |
| Patients arranged daily activities between sessions. | ESKD | HIC, LMIC | + |
| For home dialysis, training was required with extended periods off work. | ESKD | HIC, LMIC | + |
| For home dialysis, homes needed physical adaptation. | ESKD | HIC, LMIC | + |
| For home dialysis, tasks were managing treatment, monitoring, titrating medications, adopting aseptic techniques. | ESKD | HIC, LMIC | ++ |
| Pre-transplantation, specific adjustment tasks included: hospital visits, tests, and organizing payment for treatment. | ESKD | HIC, LMIC |  |
| Some people needed to negotiate donation of a kidney by living relatives or others. | ESKD | HIC, LMIC | ++ |
| Transplanted patients managed complex medication regimens. | ESKD | HIC, LMIC | + |
| Transplanted patients needed to manage relationships, finances, and family responsibilities | ESKD | HIC, LMIC | ++ |
| Symptoms associated with dialysis limited daily activities, sometimes overlooked by health professionals. | ESKD | HIC, LMIC | ++ |
| When in poor health, wider networks were necessary for daily activities, transportation, symptom management. | ESKD | HIC, LMIC | ++ |
| Information on disease and treatment was often insufficient or difficult to comprehend. | ESKD | HIC, LMIC | ++ |
| Information about immunosuppression was hard to obtain . | ESKD | HIC, LMIC | ++ |
| Lack of social support was a frequently reported problem. | ESKD | HIC, LMIC | ++ |
| Many clinicians failed to discuss care, eligibility for transplant, and potential donors. | CKD, ESKD | HIC, LMIC | ++ |
| Carers needed more information on dialysis techniques to feel confident. | ESKD | HIC | + |
| Patients and carers emphasised self-determination, autonomy and dignity when nearing end-of-life. | ESKD | HIC | ++ |

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**TITLES AND LEGENDS OF TABLES AND FIGURES**

Table 1. PICO criteria for including studies.

No legend

Table 2. Characteristics of studies included in the review.

Legend: Abbreviations: C, centre, unit, or clinic; CKD, chronic kidney disease; D, dialysis; ESKD, end-stage kidney disease; GP, general practice; H, hospital; HD, hemodialysis; NKF, National Kidney Foundation (Singapore); NP, nephrology practice; PD, peritoneal dialysis. \*includes health care staff

Table 3. Illustrative quotations.

No legend

Table 4. Summary of results

No legend

Table 5. Challenges related to burden of treatment

Legend: Abbreviations: CKD, chronic kidney disease; ESKD, end-stage kidney disease; HIC, high income country; LMIC, low- and middle income country. Severity: + mild, ++ moderate, +++ very severe.

Figure 1. PRISMA flow chart of screening and selection process

No legend

Figure 2. Thematic schema of experienced control and cognitive authority in CKD.

No legend.