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The Work of Being a Patient with Chronic Kidney Disease in Contexts of Socioeconomic Disadvantage: 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 patients and caregivers that follows from these investments and develop an understanding of burden of treatment (BoT), extending it to experiences in low- and middle-income countries.

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 256 studies from 31 countries (5063 patients and 929 carers). Socio-economic status was central to the experience of CKD and treatment. 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 CKD 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 and hospitalization is increased.[1-4] Worldwide, about 500 million people are affected by CKD; about 80% of these live in low and middle-income countries (LMIC); an estimated 1.5 million people with CKD receive renal replacement therapy (RRT) with either dialysis or transplantation.[1 5 6] 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.[7] 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.[7]

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.[8-13] 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).[8 11 14] 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.[8 14-25] 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.[11 26 27] 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.[28] The aim of this study is to develop specific understanding of treatment burden experienced by people with CKD 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.[28 29] PROSPERO registration number is CRD42014014547. This review follows the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework.[30] 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 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.[29] 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.[31] 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.[32] The coding frame drew on concepts from the Burden of Treatment Theory and the Cognitive Authority Theory.[16-19 27 33 34] 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.

RESULTS

Combined searches yielded 5407 citations and resulted in 256 studies from 31 countries included in the final analysis. Three papers did not report the number of participants, but in the remaining 253 papers, a total of 5063 patients and 929 carers were included. Countries most frequently represented in the studies were: United States with 52 (20.3%), UK with 46 (18.0%), Brazil with 28 (11%), Australia with 27 (11%), Canada with 18 (7.1%), Sweden with 18 (7.1%), New Zealand with 8 (3.1%), and Iran with 7 (2.7%) studies. Table 3 shows illustrative quotations and table 4 shows summary of results.

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.[35-50] Living as a person with CKD 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.[33 45-47 49 51-61] Poorly funded or unfunded healthcare resulted in fragmented treatment across healthcare systems.[45 46 62] 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.[38 43 46-49] Where government or private insurance coverage of CKD 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.[43 45-48 58 63] In such settings, patients received dialysis treatment only if they could afford it or when they had access to free sessions.[43 45-48 58 63] Medication was sometimes counterfeit, obtained on the black market, as legitimate medication was beyond patients' reach.[47] 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.[33 45-47 50 64] 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.[38 48 58 65 66]

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.[49 51 59 67-71] 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.[51 72-74] 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.[51 55-57 75-80]

In some countries, the transplantation procedure could be particularly expensive, even at public hospitals.[33 45-47 64 81] 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.[47 81-83] 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.[81]

Housing conditions. Unsuitable housing was a barrier to home dialysis if it could not accommodate equipment, and was impossible without an adequate electricity supply.[49 59] In rented accommodation, landlords might not approve of necessary modifications. Home dialysis was not a treatment option for those with no fixed abode.[49 59 68 84]

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.[37 43 50 58 67 70 85-89] 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.[33 50]

Patient workload

Self-care. People with CKD had complex medication regimens managed through dispensing aids, daily activities associated to medication taking such as meals, family support, or a combination of these.[38 44 69 84 90-104] 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.[64 105-108] To care for their vascular access, patients restricted themselves from lifting heavy objects, were alert for pain, or hardness, and protected the arm overall.[106 109] 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.[44 61 110-118] Women also faced potential family conflicts if they followed prescribed diets.[43 60 119-122] In certain cultures, comfort and wealth were associated with abundance of foods: this meant that restrictive diets essential to self-care were sometimes stigmatized as a sign of poverty.[60 119 123]

Travel and time management. People with CKD 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.[13 45-47 51 74 84 124-131] 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.[53 132-143] The treatment was seen by most patients as an emotional and time imposition that caused boredom and frustration.[61 144-150] Time was often spent waiting for visits, prescriptions, and tests.[53 132-143 151] Parents also arranged child care while they were in sessions, or had to travel for treatment.[47 51 53 152 153]

Home dialysis. For patients receiving home dialysis, training was required which necessitated extended periods of leave from work.[59 68 154-156] 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.[150 156-160] 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.[154 155 161] In the case of developing peritonitis, workload increased as antibiotics had to be reconstituted and injected.[154 155]

Pre-transplantation adaptation. People with CKD adjusted to being on the transplant waiting list and prepared for the possibility of receiving a kidney from a deceased donor at any time.[41 113 131 162-168] 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.[130 131 162 163 168-171] 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.[37 45 162 172]

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.[82 83 173-178] 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.[82 83 173-178] 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.[81 83 173-175 179-184]

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.[45-47] 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.[45]

Capacity

Physical and mental capacity. The ability of people with CKD 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,[35 42 53 61 88 94 136 138 152 185-198] sometimes overlooked by health professionals.[56 92 99 199-201] 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.[35 116 159 202-206] Carers were involved in the dialysis procedure, accompanying patients to dialysis and responding to psychosocial needs.[43 67 95 127 139 141 159 207-213] 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.[45 47 50 214 215]

Information deficits. Patients reported that their information on the disease and treatment options was often insufficient or difficult to comprehend, particularly during the early stages, independent of income or coverage level; the desire for more patient-centred care were widely expressed.[36 48 55 56 59 61 62 75 90 107 119 125-129 186 202 216-227] Short clinic visits, unknown technical jargon, and high levels of anxiety were barriers to accessing information.[59 100 220 228-231] For organ donation and transplantation, people with CKD usually received information through discussions with other patients, providers, social workers, financial representatives, the internet, and, in affluent populations, informative meetings.[115 172 232-235] Other patients could sometimes supply information about dialysis options, travelling, hygiene regimens, dietary restrictions, benefit advice, timing of treatment, and pain management.[115 172 232-235] 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.[176 182 183 236-239] 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.[237 239-242]

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.[37 42 58 60 212 243-251] A lack of social support was also frequently reported.[42 58 244 252] 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.[37] 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.[59 150] To demonstrate resilience, some patients tried to maintain a sense of normalcy, integrating the dialysis community into their social network.[40 137 207 253]

Experienced control

Personal control. Feelings of personal control were achieved through learning how to manage CKD, finding a balance between illness and normalcy, or even denying the seriousness of their condition.[215 253 254] The experience of feelings of personal control led to increased self-confidence and well-being.[13 187 255] 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.[137 255-260] People with CKD 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.[52 53] Lengthening treatment hours could facilitate higher than usual fluid removal or managing symptoms.[52 53] Some patients entrusted decisions entirely to the care team, and this promoted feelings of security.[59 68 100 105 261 262] 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.[13 41 59 61 195 236 263] However, even when patients knew they were not in control, they felt unsafe if the treatment went differently from what was expected.[264] Patients recognised prognostic uncertainty, and their own fear of incompetence as an obstacle to choosing the appropriate dialysis modality.[52 70 90 130 131 148 159 220 255 263 265-269] For many patients, home dialysis restored a sense of control and freedom to manage their schedule, especially if it was nocturnal.[49 68 156 217 258 270] Dependence on emergency care or on fund-raising tasks to cover life-saving treatment represented a severe case of lack of experienced control.[33 45-47 50 64]

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.[233] 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.[199 265 268 269 271-274] Home dialysis patients appreciated training to build confidence and skills to utilise the machine.[52 68 109 265 275 276] 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.[53 56 277] People with CKD whose clinicians failed to discuss care, eligibility and ineligibility for transplant, and potential donors with them felt disempowered.[37 53 55 56 75 76 167 278] 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.[170 179 232] 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.[47 61 87 94 165 279-281]

Carers' involvement. Relatives wanted to be involved in discussions on dialysis modality as dialysis would take up a large part of their lives.[53 68 109 154-156 220 275 282] 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.[59 67] Family members were afraid to bother the healthcare team[256], 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.[207] To cope with caring, carers sought support in psychiatric help or religion when available, or support in religion.[139 244] 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.[132 139 159]

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. [233 283 284] Family members felt ACP was necessary as a means to protect patients.[285-287] At the end-of-life, maintaining control was a struggle with respect to autonomy and dignity.[132 134 202 255] 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.[126 288] For some, the decision to withdraw from dialysis meant asserting their self-determination.[255 289] 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.[62 126 132 159] 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.[199 230 287] 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 are often under-insured or not at all, which makes it almost impossible for them to attain life-saving treatments. Patients 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.[290-303] Here, we focused on three elements of BoT, namely workload, capacity and experienced control, to develop an understanding of the BoT of CKD including the experiences of patients in contexts of structural inequalities.

Worldwide, many individuals with CKD receive no treatment or receive only fragmented care.[6 33 304-309] Millions of preventable deaths occur because of lack of access to RRT.[7] 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.[310] One example is the use of emergency haemodialysis by undocumented and uninsured immigrants with CKD.[50] Several studies have highlighted the imperative necessity to address this disturbing reality.[311-318]

When health systems fail to meet patients' treatment needs, patients mobilise resources and develop coping strategies such as accepting charity or selling assets.[11 27 307] 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. 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.

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.[19 249 250 319-323] 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.[42 58 244 252] 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.[324] 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.[18 28 291 303 325] 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.[324] 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.[301]

Our findings confirm that among immigrant populations, language, cultural, and religious differences can act as barriers to healthcare and contribute to BoT; culturally competent community navigator programs could play an essential role in improving healthcare disparities.[326] Surprisingly, patients who undergo haemodialysis tend to perceive that staff underestimate their capacities.[56 92 99 199-201] 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.[26 327]

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.[28 328] When overwhelmed, patients may be forced to renegotiate their responsibilities with actors in the health system and their own social networks.[27]

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.

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.[6 307] 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; LMIC, low- and middle-income countries.

DECLARATIONS

Ethics approval and consent to participate

Not applicable

Consent to publish

Not applicable

Availability of data and material

EXPERTS1 Protocol is published in BMJ Open, with open access

May CR, Masters J, Welch L, Hunt K, Pope C, Myall M, Griffiths P, Roderick P, Glanville J, Richardson A: **EXPERTS 1—experiences of long-term life-limiting conditions among patients and carers: protocol for a qualitative meta-synthesis and conceptual modelling study**. *BMJ open* 2015, **5**(4):e007372.

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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	Patients	Carers	Data collection	Data analysis reported
Aasen[105]	2012	Norway	11		Interviews	Critical discourse analysis
Aasen [256]	2012	Norway		7	Interviews	Critical discourse analysis
Al-Arabi [102]	2006	United States	80		Interviews	Naturalistic inquiry, thematic analysis
Allen [171]	2011	Canada	7		Ethnographic observations, interviews	Participatory action, thematic analysis
Allen [62]	2015	Canada	6	11	Ethnographic observations, interviews	Thematic analysis
Anderson [51]	2012	Australia	241		Interviews	Thematic analysis
Anderson [75]	2008	Australia	241		Interviews	Thematic analysis
Arslan [198]	2009	Turkey	10		Interviews	Content analysis
Ashby [36]	2005	Australia	16		Interviews	Grounded theory
Avril-Sephula [116]	2014	United Kingdom	8		Interviews	Thematic analysis
Axelsson [132]	2015	Sweden		14	Interviews	Content analysis
Axelsson [185]	2012	Sweden	8		Interviews	Phenomenological, hermeneutical analysis
Bailey [232]	2015	United Kingdom	32		Interviews	Constant comparison
Bailey [37]	2016	United Kingdom	13		Interviews	Constant comparison
Baillie [154]	2015	United Kingdom	16	9	Interviews	Thematic analysis
Baillie [155]	2015	United Kingdom	16	9	Interviews	Thematic analysis
Barbosa [143]	2009	Brazil	10		Interviews	Grounded theory
Bath [243]	2003	United Kingdom	10		Interviews	Phenomenological analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Beanlands [207]	2005	Canada		37	Interviews	Grounded theory
Bennett [195]	2013	Australia	9	2	Interviews facilitated by images	Thematic analysis
Blogg [67]	2008	Australia		5	Interviews	Ethnographic analysis
Boaz[173]	2014	United Kingdom	25		Interviews	Constant comparison
Bourbonnais [103]	2012	United States	25		Interviews	Content analysis
Bridger [235]	2009	United Kingdom	23		Interviews, drawings, journals	Grounded theory
Bristowe [124]	2015	United Kingdom	20		Interviews	Thematic analysis
Brito-Ashurst, de [119]	2011	United Kingdom	20		Focus groups, vignettes and diaries	Thematic analysis
Browne [223]	2016	United States	40		Focus groups	Content analysis
Buldukoglu[184]	2005	Turkey	40		Open ended questions	Constant comparison
Burnette [76]	2009	Australia	6		Interviews	Thematic analysis
Cadena [152]	2015	Mexico	5		Interviews	Interpretative phenomenological analysis
Calvey [144]	2011	Ireland	7		Interviews	Colaizzi's method
Calvin [255]	2004	United States	12		Interviews	Constant comparison
Calvin [287]	2014	United States	18		Interviews	Interpretative, Glaserian approach
Campos [231]	2003	Brazil	7		Interviews	Thematic analysis
Campos [85]	2010	Brazil	7		Interviews	Thematic analysis
Campos [86]	2015	Brazil	23		interviews	Content analysis
Cases [275]	2011	United Kingdom	6		Interviews	Phenomenological analysis
Cervantes [50]	2017	United States	20		Interviews	Thematic analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Chatrung [186]	2015	Thailand	8		Interviews	Thematic analysis
Chenitz [84]	2014	United States	30		Interviews	Grounded theory
Chiaranai [38]	2016	Thailand	26		Interviews	Thematic analysis
Cho [39]	2016	Korea	5		Interviews	Colaizzi's method
Chong [162]	2016	Korea	8		Interviews	Content analysis
Clarkson [104]	2010	United States	10		Interviews	Thematic analysis
Costa [196]	2014	Brazil	26		Interviews	Lexical analysis
Costantini [90]	2008	Canada	14		Interviews	Content analysis
Cox [146]	2016	United States	50		Interviews	Interpretive description
Cramm [216]	2015	The Netherlands	15	12	Interviews	Factor analysis, Q methodology
Cristóvao [111]	2013	Portugal	20		Interviews	Thematic analysis
Crowley-Matoka[81]	2005	Mexico	50		Interviews	NA
Curtin [259]	2002	United States	18		Interviews	Content analysis
Curtin [260]	2001	United States	18		Interviews	Content analysis
da Silva [101]	2016	Brazil	30		Interviews	Content and thematic analysis
da Silva [329]	2011	Brazil	9		Interviews	Qualitative analysis
Darrell [277]	2016	United States	12		Interviews	Giorgi's method
Davison [228]	2006	Canada	24		Interviews	Constant comparison, iterative analysis
Davison [286]	2006	Canada	19		Interviews	inductive analysis
de Brito [87]	2015	Brazil	50		Interviews	Collective subject technique

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
de Rosenroll [273]	2013	Canada		10	Interviews	Constant comparison
Dekkers [40]	2005	The Netherlands	7		Interviews	Phenomenological analysis
DePasquale [218]	2013	United States	68	62	Group interviews	Mixed method
dos Reis [153]	2008	Brazil	8		Interviews	Content analysis
dos Santos [160]	2011	Brazil	8		Interviews	Grounded theory
dos Santos [252]	2015	Brazil	20		Interviews	Critical incident analysis
Ekelund [41]	2010	Sweden	39	21	Interviews	Content analysis
Erlang [200]	2015	Denmark	9		Interviews	Systematic text condensation
Eslami [211]	2016	Iran		20	Interviews	Thematic analysis
Finnegan-John [88]	2013	United Kingdom	118	12	Interviews and focus groups	Thematic analysis
Flores [163]	2004	Brazil	9		Interviews	Content analysis
Fraguas [35]	2008	Brazil		18	Interviews	Content analysis
Ghadami[236]	2012	Iran	15		Interviews	Content analysis
Giles [157]	2003	Canada	4		Interviews	Thematic analysis
Giles [158]	2005	Canada			Interviews	Phenomenological analysis
Goff [283]	2015	United States	13	9	Interviews	Thematic analysis
Goldane[174]	2011	United States	39		Focus groups and interviews	Iterative analysis
Gordon[178]	2007	United States	20		Diary entries	Thematic analysis
Gordon[82]	2009	United States	82		Interviews	Thematic analysis
Gricio [112]	2009	Brazil	20		Interviews	Thematic analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Gullick [330]	2016	Australia	11	5	Interviews	Hermeneutic interpretation
Hagren [113]	2005	Sweden	41		Interviews	Content analysis
Hagren [278]	2001	Sweden	15		Interviews	Content analysis
Hain [187]	2011	United States	56		Interviews	Story inquiry method
Hanson [68]	2016	Australia	20		Interviews	Thematic analysis
Harrington [279]	2016	United Kingdom	24		Interviews	Thematic analysis
Harwood [265]	2014	Canada	13		Interviews	Content analysis
Harwood [271]	2005	United Kingdom	11		Interviews	Content analysis
Haspeslagh[237]	2013	Belgium	31		Interviews and questionnaires	Thematic analysis
Heiwe [135]	2003	Sweden	16		Interviews	Contextual analysis
Heiwe [138]	2004	Sweden	16		Interviews	Contextual analysis
Herbias [114]	2016	Chile	12		Interviews	Streubert's method
Herlin [280]	2010	Sweden	9		Interviews	Giorgi's method
Hollingdale [224]	2008	United Kingdom	20		Focus groups	Framework approach
Hong [118]	2017	Singapore	14		Interviews	Thematic analysis
Horigan [136]	2013	United States	14		Interviews	Content analysis
Hutchison [285]	2017	Canada	9	16	Interviews	Interpretive description
Iles-Smith [229]	2005	United Kingdom	10		Interviews	Thematic analysis
Johnston [126]	2012	United Kingdom	9		Interviews	Thematic analysis
Kaba [331]	2007	Greece	23		Interviews	Qualitative analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Kahn [33]	2015	United States	34		Interviews	Thematic analysis
Karamanidou [13]	2014	United Kingdom	7		Interviews	Interpretative and phenomenologic analysis
Kazley [42]	2015	United States	20		focus groups	Thematic analysis
Keeping [71]	2001	Canada	8		Interviews	Thematic analysis
Kierans [164]	2005	Ireland	5		Interviews	Phenomenological analysis
Kierans [165]	2001	Ireland	5		Interviews, life stories	Phenomenological analysis
King [89]	2002	United Kingdom	22		Interviews	Template approach
Knihs [166]	2013	Brazil	20		Interviews	Content analysis
Krespi-Boothby [145]	2004	United Kingdom	16		Interviews	Thematic analysis
Krespi-Boothby [149]	2013	United Kingdom	16		Interviews	Template approach
Ladin [199]	2016	United States	23		Interviews	Thematic analysis
Ladin [264]	2017	United States	31		Interviews	Thematic analysis Nutbeam's framework
Landreneau [269]	2006	United States	6		Interviews	Colaizzi's method
Landreneau[274]	2007	United States	12		Interviews	Colaizzi's method
Lawrence [167]	2013	United Kingdom	10		Interviews	Conceptual and categorical analysis
Lederer [261]	2015	United States	32		Interviews	Thematic analysis
Lee [220]	2008	Denmark	27	18	Focus groups	Thematic analysis
Lee [43]	2016	Singapore		20	Interviews	Thematic analysis
Lenci [248]	2012	United States	4		Interviews	Thematic analysis
Leung[179]	2007	Hong Kong	12		Interviews	Content analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Lewis [281]	2015	United Kingdom	40		Interviews	Grounded theory
Lin [188]	2015	Taiwan	15		Interviews	Constant comparison
Lindberg [257]	2013	Sweden	10		Interviews	Content analysis
Lindberg [44]	2008	Sweden	10		Interviews	Content analysis
Lindsay [276]	2014	Australia	7		Interviews	Thematic analysis
Llewellyn [266]	2014	United Kingdom	19		Interviews	Thematic analysis
Lo [127]	2016	Australia	58		Interviews and focus groups	Thematic analysis
Lopes [168]	2014	Brazil	12		Interviews	Interpretative analysis
Lopez-Vargas [91]	2016	Australia	38		Focus groups	Thematic analysis
Lopez-Vargas [92]	2014	Australia	38		Focus groups	Thematic analysis
Lovink [214]	2015	The Netherlands	12		Interviews	Content analysis
Low [159]	2014	United Kingdom		26	Interviews	Thematic analysis
Machado [147]	2003	Brazil	18		Interviews	Discourse analysis
Marques [225]	2014	Brazil		10	Interviews	Content analysis
Martin-McDonald[192]	2003	Australia	10		Interviews	Thematic analysis
Martin-McDonald [193]	2003	Australia	10		Interviews	Thematic analysis
Mason [93]	2007	United Kingdom	9	5	Focus groups	Framework approach
McCarthy [161]	2010	Australia	5		Interviews	Sequential analysis
McKillop [262]	2013	United Kingdom	10		Interviews	Thematic analysis
Mercado-Martínez [45]	2015	Mexico	37	50	Interviews	Content analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Mercado-Martínez [47]	2014	Mexico	21		Interviews	Thematic analysis
Mercado-Martínez[46]	2015	Brazil	11	5	Interviews	Content analysis
Mitchell [202]	2009	United Kingdom	10		Interviews	Content analysis
Molzahn [289]	2012	United States	14		Interviews	Thematic analysis
Moran [131]	2011	Ireland	16		Interviews	Interpretative analysis
Moran [201]	2009	Australia	16		Interviews	Interpretive analysis
Moran [148]	2009	Australia	16		Interviews	Interpretive analysis
Morton [77]	2010	Australia	95		Interviews	Thematic analysis
Muduma [94]	2016	France	37		Focus groups	Qualitative analysis
Nagpal [215]	2017	United States	36		Interviews	Coding
Namiki [217]	2010	Australia	4		Interviews	Thematic analysis
Niu [194]	2017	China	23		Interviews	Continuous comparison analysis
Nobahar [65]	2016	Iran	8	12	Interviews	Graneheim Lundman content analysis
Nobahar [66]	2016	Iran	8	12	Interviews	Granheim and Lundman's approach
Noble [95]	2012	United Kingdom		19	Interviews	Constant comparison
Noble [96]	2010	United Kingdom	30	17	Interviews	Constant comparison
Noble [288]	2009	United Kingdom	30	17	Interviews	Constant comparison
Nygardh [284]	2011	Sweden		12	Interviews	Content analysis
Nygardh [233]	2011	Sweden	20		Interviews	Latent content analysis
Malheiro Oliveira [206]	2012	Brazil	19		Interviews	Categorical analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Orr[180]	2007	United Kingdom	26		Focus groups	Thematic analysis
Orr[181]	2007	United Kingdom	26		Focus groups	Thematic analysis
Oyegbile [63]	2016	Nigeria		15	Interviews	Content analysis
Pelletier-Hibbert [282]	2001	Canada		41	Focus groups	Thematic analysis
Piccoli [221]	2010	Italy	12		Focus groups	Not clear
Pietrovski [205]	2006	Brazil	15		Interviews	Content analysis
Pilger [222]	2010	Brazil	22		Interviews	Thematic analysis
Polaschek [52]	2003	New Zealand	6		Interviews	Thematic analysis
Polaschek [53]	2006	New Zealand	20		Interviews	Thematic analysis
Polaschek [54]	2007	New Zealand	20		Interviews	Thematic analysis
Prieto [128]	2011	Spain	22		Interviews	Discourse analysis
Rabiei [139]	2015	Iran		20	Interviews	Thematic analysis
Ravenscroft [253]	2005	Canada	7		Interviews	Inductive analysis
Reid [263]	2012	United Kingdom	11		Interviews	Thematic analysis
Reta [129]	2014	Spain	14		Interviews	Content analysis
Richard [106]	2010	United States	14		Interviews	Cultural negotiation model framework
Rifkin [97]	2010	United States	20		Interviews	Thematic analysis
Rix [55]	2015	Australia	18	29	Interviews	Thematic analysis
Rix [56]	2014	Australia	18		Interviews	Thematic analysis
Rodrigues [189]	2011	Brazil	8		Interviews	Categorical analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Ros[241]	2012	United States	19		Focus groups	Thematic analysis
Roso [117]	2013	Brazil	15		Narrative interviews	Thematic analysis
Russ [226]	2005	United States	43		Interviews	Anthropologic study
Russell[238]	2003	United States	16		Interviews	Constant comparison analysis
Rygh [69]	2012	Norway	11		Interviews	Inductive, actor's point of view
Sadala [70]	2012	Brazil	19		Narrative interviews	Phenomenological and hermeneutical analysis
Sahaf [219]	2017	Iran	9		Interviews	Van Manem thematic analysis
Salvalaggio [80]	2003	Canada	12		Interviews	Immersion/crystalization analysis
Schell [267]	2012	United States	29	11	Interviews and focus groups	Thematic analysis
Schipper[182]	2014	The Netherlands	30		Focus groups and interviews	Thematic analysis
Schmid-Mohler[83]	2014	Switzerland	12		Interviews	Content analysis
Schober [203]	2016	United States	48		Interviews	Thematic analysis
Seah [48]	2013	Singapore	9		Interviews	Interpretative phenomenological analysis
Shahgholian [140]	2015	Iran	17		Interviews	Colaizzi's method
Shaw [270]	2015	New Zealand	24		Interviews	Phenomenological analysis
Sheu[242]	2012	United States	27	23	Focus groups	Thematic analysis
Shih [57]	2011	New Zealand	7		Interviews	Hermeneutical and thematic analysis
Shirazian [121]	2016	United States	23		focus groups	Thematic analysis
Sieverdes [172]	2015	United States	27		focus groups	Thematic analysis
Smith [204]	2010	United States	19		focus groups	Content analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Spiers [169]	2016	United Kingdom	10		Interviews	Thematic analysis
Spiers[175]	2015	United Kingdom	4		Interviews	Interpretative phenomenological
Stanfill[176]	2012	United States	7		Focus groups	Iterative
Stewart [79]	2012	United States	19		Interviews	Coding
Tanyi [190]	2008	United States	16		Interviews	Colaizzi's method
Tanyi [191]	2008	United States	16		Interviews	Colaizzi's method
Tavares [213]	2016	Brazil		19	Interviews and groups	Content analysis
Taylor [109]	2016	Australia	26		Interviews	Thematic analysis
Taylor [212]	2015	United Kingdom	15	11	Interviews	Constant comparison
Theofilou [120]	2013	Greece	10		Interviews	Phenomenological analysis
Thomé [244]	2011	Brazil		10	Interviews	Cultural analysis
Tielen[177]	2011	The Netherlands	26		Interviews	Q methodology
Tijerina [74]	2006	United States	26		Interviews	Coding
Tong [234]	2015	Australia	15		Interviews	Thematic analysis
Tong[150]	2013	Italy	22	20	Interviews	Thematic analysis
Tong[61]	2009	Australia	63		Focus groups	Thematic analysis
Tonkin-Crine [125]	2015	United Kingdom	42		Interviews	Thematic analysis
Torchi [151]	2014	Brazil	10		Interviews	Collective subject technique
Tovazzi [115]	2012	United States	12		Interviews	Phenomenological analysis
Tweed [107]	2005	United Kingdom	9		Interviews	Phenomenological analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Urstad[239]	2012	Norway	15		Interviews	Hermeneutic analysis
Valsaraj [58]	2014	India	10		Interviews	Phenomenological analysis
Velez [98]	2006	Spain	12		Interviews	Thematic analysis
Vestman [258]	2014	Sweden	9		Written narratives	Thematic analysis
Visser [272]	2009	The Netherlands	14		Interviews	Thematic analysis
Wachterman [170]	2015	United Kingdom	16		Interviews	Thematic analysis
Walker [122]	2012	United Kingdom	9		Interviews	Thematic analysis
Walker [49]	2016	New Zealand	43	9	Interviews	Thematic analysis
Walker [59]	2016	New Zealand	43	9	Interviews	Thematic analysis
Walker [78]	2017	New Zealand	13		Interviews	Thematic analysis
Walton [249]	2007	United States	21		Interviews	Grounded theory
Walton [251]	2002	United States	11		Interviews	Grounded theory
Weil [245]	2000	United States	14		Interviews	Thematic analysis
Wells [246]	2015	United States	17	17	Interviews	Thematic analysis
Wells [60]	2015	United States	15	21	Interviews	Thematic analysis
White [137]	2004	United States	6	9	Interviews	Thematic analysis
Wiederhold[183]	2012	Germany	10		Interviews	Content analysis
Wilkinson [230]	2014	United Kingdom	16	45	Interviews and focus groups	Thematic analysis
Wilkinson [72]	2016	United Kingdom	16	45	Interviews and focus groups	Thematic analysis
Wilkinson [73]	2011	United Kingdom	48		Interviews	Thematic analysis

Author	Year	Country	Patients	Carers	Data collection	Data analysis reported
Williams [99]	2009	Australia	20		Interviews	Qualitative analysis
Williams [100]	2008	Australia	23		Interviews and focus groups	Interpretative analysis
Williams [254]	2009	Australia	23		Interviews	Qualitative analysis
Wilson [247]	2015	United Kingdom	15	15	Focus groups	Thematic analysis
Winterbottom [227]	2012	United Kingdom	20		Interviews	Thematic analysis
Wu [64]	2015	Taiwan	15		Interviews	Thematic analysis
Xi [156]	2013	Canada	10		Interviews	Thematic analysis
Xi [108]	2011	Canada	13		Interviews	Thematic analysis
Yeun [141]	2016	Korea		33	Interviews	Q methodology
Yngman-Uhlin [133]	2010	Sweden	14		Interviews	Phenomenological analysis
Yngman-Uhlin[130]	2016	Sweden	8		Interviews	Content analysis
Yodchai [250]	2016	Thailand	20		Interviews	Qualitative analysis
Yodchai[197]	2012	Thailand	5		Interviews	Grounded Theory
Yu [110]	2014	Singapore	32		Interviews	Thematic analysis
Yumang [142]	2009	Canada	9		Interviews	Colaizzi's method
Ziegert [208]	2006	Sweden		13	Interviews	Content analysis
Ziegert [209]	2009	Sweden	20		Interviews	Content analysis
Ziegert [210]	2001	Sweden		12	Interviews	Pragmatic approach

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).[50] 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).[45]
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).[84]
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).[37]
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).[156]
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).[63]
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).[202]

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.[33 35-61].
		Treatment costs were major obstacle to care [45-47 62] as was limited access to healthcare for the un- or under-insured.[33 38 46 48 50 58 65 66]
		Transplants, dialysis and drug treatments were often beyond the reach of low-income patients.[33 45-47 64 81-83]
		Un- or under-insured people experienced increased dependence on emergency care.[33 45-47 50 64].
		Poorly funded or unfunded healthcare was often fragmented and of indeterminate duration.[45 46 62]
		For non-native speakers, language was an important barrier for having a discussion with care providers.[51 72-74]
		Patients were often poorly informed about disease progression and treatment options.[36 48 55 56 61 62 125-127 186 202 216-219]
	Housing	Homelessness, unsuitable housing, lack of utilities (electricity, clean running water) are critical to self-care and home dialysis.[49 59 68 84]
	Employment status.	Loss of employment may lead to un- or under-insurance that limits or prevents access to treatment.[33 37 43 50 58 67 70 85-89]
Workload	*Self-care*.	Complex medication regimens were managed through dispensing aids, associated activities, family support.[38 44 69 84 90-101]
		When taking care of their vascular access, patients made efforts to protect the arm.[106 109]
		Patients controlled their diets and fluid intake, and managed food cravings and thirst.[61 110]
		Many modified social activities to minimise exposure to hot weather, temptation, and social pressure.[110 116-118]
		Women could face family conflicts if they followed prescribed diets.[43 60 119-122]
		Restrictive diets were sometimes stigmatized as a sign of poverty.[119]
	Fund-raising.	Fund raising was important for those who were un- or under-insured, sold goods or services, organised raffles, or obtained loans.[45-47]
		Patients contacted centres, other patients, and organisations to ask for free treatment when they were un – or under-insured.[45 47 50 214 215].
	Travel and time	Patients often travelled for long distances to dialysis centres, 3 times a week.[13 45-47 51 74 84 124-131]

	management.	Home dialysis patients had to pay transport to training, appointments, and other check-ups.[51 59 67-70] Patients arranged daily activities between sessions, adjusted activities to their fatigue, and tried to schedule medical appointments all on one day.[53 132-143] Parents arranged child-care while they were in sessions or when they were tired.[47 51 53 152 153]
	Home dialysis.	Training was required with extended periods off work.[59 68 154-156] Homes needed physical adaptation, carers invested efforts in maintaining cleanliness and hygiene.[150 156-160] Specific tasks were managing treatment at set times, recording blood pressure and body weight, titrating medications, adopting aseptic techniques.[154 155 161]
	Pre-transplant adaptation.	Patients adjusted to being on transplant waiting-list, prepared for transplant from a deceased donor at any time.[41 113 131 162-168] Specific adjustment tasks included: hospital visits, tests, and organizing payment for treatment.[130 131 162 163 168-171] Some people needed to negotiate donation of a kidney by living relatives or others.[37 45 162 172]
	Post-transplant adjustment.	Transplanted patients managed complex medication regimens, balanced against the need to re-enter the labour market to pay off loans.[82 83 173-178] Post-transplant, patients needed to manage relationships, finances, and family responsibilities in context of prognostic uncertainty[81 83 173-175 179-184]
Capacity	*Physical and mental capacity*	Daily activities were limited by symptoms associated with dialysis (pain, fatigue, anxiety, and depression).[35 42 53 61 88 94 136 138 152 185-197] Symptoms were sometimes overlooked by health professionals.[56 92 99 199-201] When in poor health, patients relied on wider networks for food preparation, transportation, shopping, ordering supplies, symptom management, and training.[35 116 159 202-205] Carers were involved in the treatment, accompanying patients to dialysis and responding to psychosocial needs.[43 67 95 127 139 141 159 207-212]
	Information deficits.	Information on disease and treatment was often insufficient or difficult to comprehend, particularly during early stages.[59 75 90 107 119 128 129 220-224] Short clinic visits, jargon, and anxiety were barriers to accessing information.[59 100 220 228-231]

		For organ donation and transplantation, patients relied on information from other patients, health professionals, social workers, financial representatives, meetings and the internet.[115 172 232-235] Information about the effects and side-effects of immunosuppression was important but hard to come by.[176 182 183 236-239] Stress and urgency affected how people with CKD processed information provided by healthcare professionals.[237 239-242]
	Social support.	Support from friends, family, neighbours, health professionals and other patients was essential.[37 42 58 60 212 243-248] Lack of social support was a frequently reported problem.[42 58 244 252] Patients ought to maintain a sense of normalcy, integrating dialysis community into their network.[40 137 207 253] Younger patients sometimes considered home dialysis as an opportunity for employment and contact with social networks.[59 150]
Experienced control	*Personal control and decision-making*	When clinicians failed to discuss care, eligibility for transplant, and potential donors, patients felt disempowered.[37 53 55 56 75 76 167 278] 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.[170 179 232] Once transplanted, main clinical objective was preserving the graft.[47 61 87 94 165 279-281]
	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.[53 68 109 154-156 220 275 282] 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.[132 139 159]
	End-of-life decisions.	Patients and carers emphasised self-determination, autonomy and dignity.[132 134 202 255 289] End-of-life decisions were influenced by ideas about personal fulfilment, nature taking its course, fears of dependence, or of dialysis accelerating death.[126 288] Decisions often passed to trusted carers or professionals.[285-287] Acceptance of decisions was influenced by treatment modality, patient age, and ineffectiveness of haemodialysis.[62 126 132 159] Families emphasized importance of respecting patients' wishes.[199 230 287]

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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.

No legend

Table 3. Illustrative quotations.

No legend

Table 4. Summary of results

No legend

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.

Figure 1

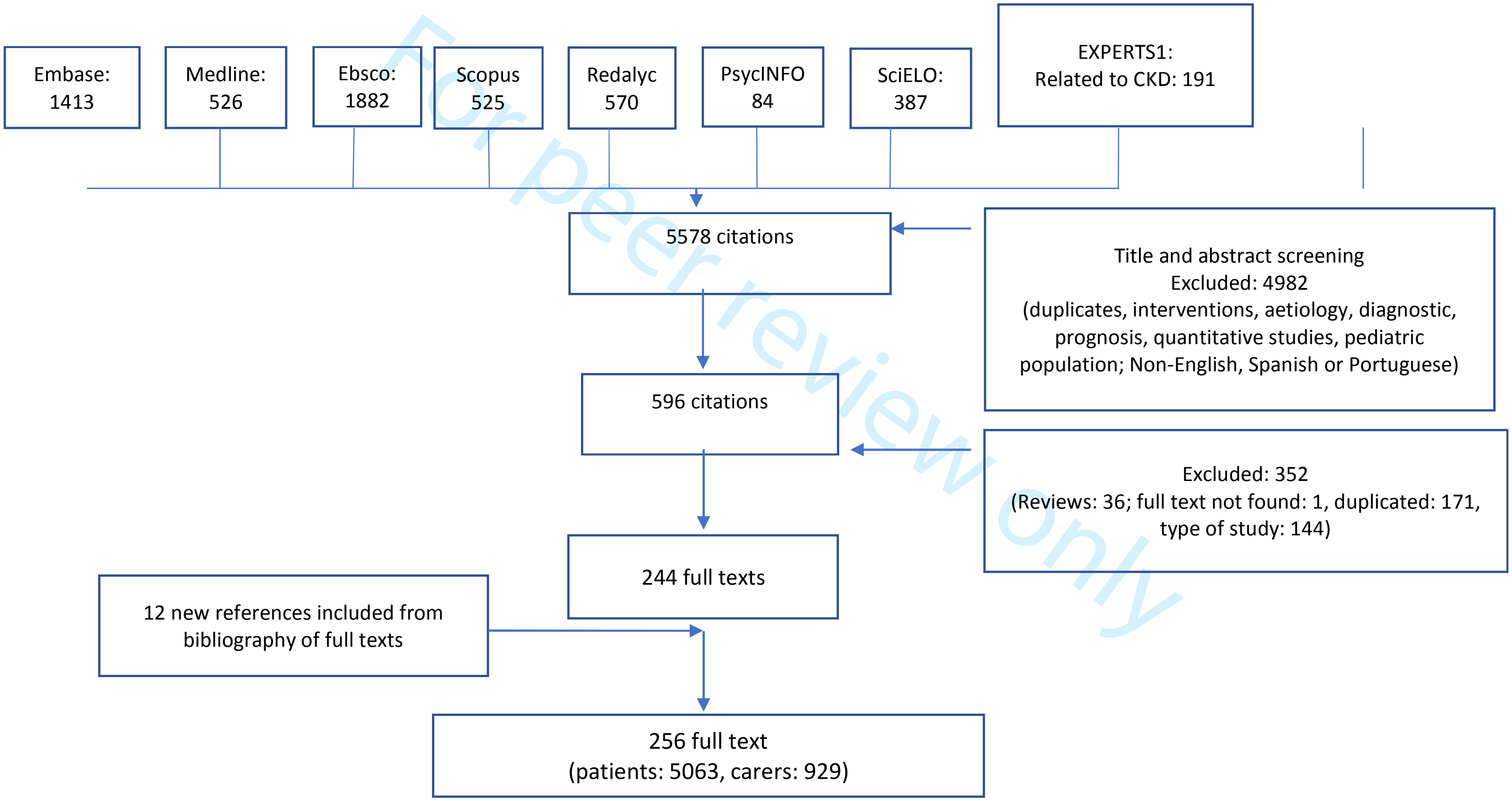
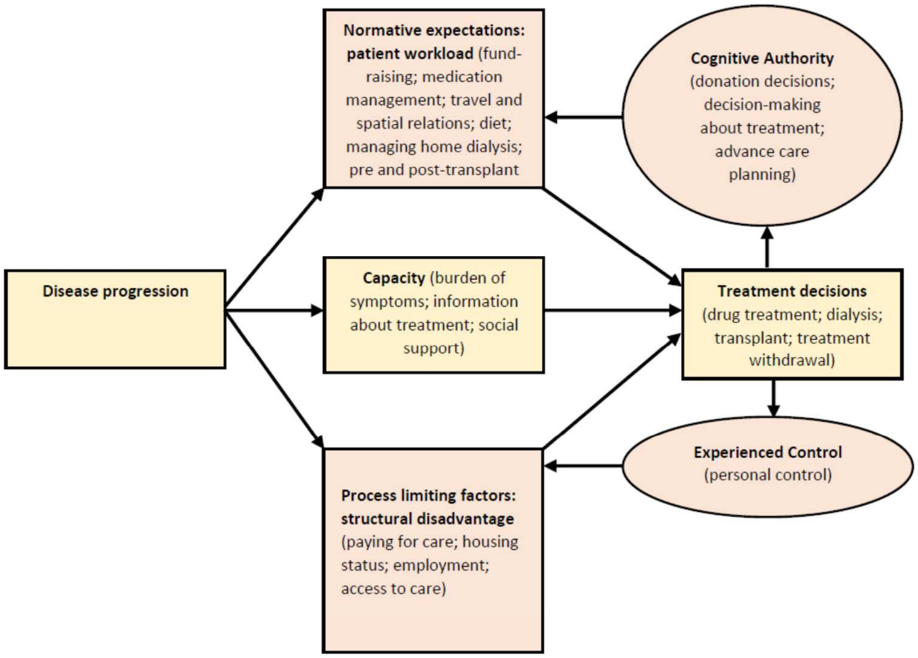

Embase: 1413
Medline: 526
Ebsco: 1882
Scopus 525
Redalyc 570
PsycINFO 84
SciELO: 387
EXPERTS1: Related to CKD: 191
5578 citations
Title and abstract screening
Excluded: 4982
(duplicates, interventions, aetiology, diagnostic, prognosis, quantitative studies, pediatric population; Non-English, Spanish or Portuguese)
596 citations
Excluded: 352
(Reviews: 36; full text not found: 1, duplicated: 171, type of study: 144)
244 full texts
12 new references included from bibliography of full texts
256 full text
(patients: 5063, carers: 929)

Figure 2


Normative expectations: patient workload (fund-raising; medication management; travel and spatial relations; diet; managing home dialysis; pre and post-transplant
Cognitive Authority (donation decisions; decision-making about treatment; advance care planning)
Disease progression
Capacity (burden of symptoms; information about treatment; social support)
Treatment decisions (drug treatment; dialysis; transplant; treatment withdrawal)
Experienced Control (personal control)
Process limiting factors: structural disadvantage (paying for care; housing status; employment; access to care)

Appendix 1. Search strategy

1 exp Renal Insufficiency, Chronic/
2 Renal Insufficiency/
3 exp Renal Replacement Therapy/
4 Hemodialysis Units, Hospital/
5 (chronic kidney or chronic renal or chronic nephropath*).ti,ab,kf.
6 (kidney failure*1 or renal failure*1).ti,ab,kf.
7 (renal insufficienc* or kidney insufficienc*).ti,ab,kf.
8 (dialysis or predialysis).ti,ab,kf.
9 (hemodialysis or haemodialysis).ti,ab,kf.
10 (hemofiltration or haemofiltration).ti,ab,kf.
11 (hemodiafiltration or haemodiafiltration).ti,ab,kf.
12 (end-stage renal or end-stage kidney or endstage renal or endstage kidney).ti,ab,kf.
13 (stage 5 and (renal disease*1 or kidney disease*1)).ti,ab,kf.
14 (kidney transplant* or renal transplant* or kidney graft* or renal graft* or kidney replacement*1 or renal replacement*1).ti,ab,kf.
15 (CKF or CKD or CRF or CRD).ti,ab,kf.
16 (ESKD or ESRD or ESKF or ESRF).ti,ab,kf.
17 (CAPD or CCPD or APD).ti,ab,kf.
18 or/1-17
19 exp qualitative research/
20 qualitativ*.ti,ab,kf.
21 interviews as topic/
22 interview*.ti,ab,kf.
23 focus groups/
24 focus group*1.ti,ab,kf.
25 grounded theory/ or (grounded theor* or grounded study or grounded studies or grounded research or grounded analys*).ti,ab,kf.
26 phenomenol*.ti,ab,kf.
27 (ethnograph* or ethnonurs* or ethno-graph* or ethno-nurs*).ti,ab,kf.
28 (story or stories or storytelling or narrative*1 or narration*1).ti,ab,kf.
29 (open-ended or open question* or text*).ti,ab,kf.
30 Narration/ or personal narratives/ or personal narratives as topic/
31 (discourse* analys* or discurs* analys*).ti,ab,kf.
32 content* analys*.ti,ab,kf.
33 ethnological.ti,ab,kf.
34 purposive sampl*.ti,ab,kf.
35 (constant comparative or constant comparison*1).ti,ab,kf.
36 theoretical sampl*.ti,ab,kf.
37 (theme* or thematic*).ti,ab,kf.
38 (emic or etic or hermeneutic* or heuristic* or semiotic*).ti,ab,kf.
39 data saturat*.ti,ab,kf.
40 participant observ*.ti,ab,kf.

41 exp Humanism/ or (humanistic* or existential* or experiential* or paradigm*).ti,ab,kf.

42 Postmodernism/ or (social construct* or postmodern* or post-modern* or poststructural* or post-structural* or feminis* or constructivis*).ti,ab,kf.

43 (action research or cooperative inquir* or co-operative inquir*).ti,ab,kf.

44 human science.ti,ab,kf.

45 biographical method*.ti,ab,kf.

46 life world.ti,ab,kf.

47 theoretical saturation.ti,ab,kf.

48 group discussion*1.ti,ab,kf.

49 direct observation*.ti,ab,kf.

50 mixed method*.ti,ab,kf.

51 (observational method* or observational approach*).ti,ab,kf.

52 key informant*1.ti,ab,kf.

53 (field study or field studies or field research* or field work* or fieldwork*).ti,ab,kf.

54 (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kf.

55 "face-to-face".ti,ab,kf.

56 ((guide or structured) adj5 (discussion*1 or questionnaire*1)).ti,ab,kf.

57 (heidegger* or colaizzi* or speigelberg* or van manen* or van kaam* or merleau ponty* or husserl* or giorgi* or foucault* or corbin* or glaser*).ti,ab,kf.

58 or/19-57

59 Consumer Behavior/

60 attitude/ or exp attitude to health/ or Attitude to Death/

61 personal satisfaction/

62 exp Emotions/

63 Stress, psychological/

64 exp Patients/px

65 Caregivers/px

66 professional-patient relations/ or nurse-patient relations/ or physician-patient relations/

67 professional-family relations/

68 Empathy/

69 Feedback/

70 ((patient*1 or client*1 or user*1 or consumer*1 or personal or carer*1 or caregiver*1 or care-giver* or family*1 or families) and (experienc* or perspective*1 or perception*1 or opinion*1 or account or accounts or attitude*1 or view or views or viewpoint*1 or satisf* or unsatisf* or dissatisf* or disatisf* or belief*1 or believ*)).ti.

71 ((patient*1 or client*1 or user*1 or consumer*1 or personal or carer*1 or caregiver*1 or care-giver* or family*1 or families) adj3 (experienc* or perspective*1 or perception*1 or opinion*1 or account or accounts or attitude*1 or view or views or viewpoint*1 or satisf* or unsatisf* or dissatisf* or disatisf* or belief*1 or believ*)).ab,kf.

72 ((patient*1 or client*1 or user*1 or consumer*1 or personal or carer*1 or caregiver*1 or care-giver* or family*1 or families) and (emotion* or feeling*1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet* or anxious* or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat* or stress* or distress* or embarrass* or empath* or accept* or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother* or unbother* or pleased or displeased* or concern* or burden* or hassl* or convenien* or

inconvenien* or confus* or hope or hopeless or hopeful or trust or trusts or mistrust* or distrust* or entrust* or trusting or trusted or confiden* or unconfiden*)).ti.

73 ((patient* or client* or user* or consumer* or personal or carer* or caregiver* or care-giver* or family* or families) adj3 (emotion* or feeling* or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet* or anxious* or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrate* or stress* or distress* or embarrass* or empath* or accept* or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother* or unbother* or pleased or displeased* or concern* or burden* or hassl* or convenien* or inconvenien* or confus* or hope or hopeless or hopeful or trust or trusts or mistrust* or distrust* or entrust* or trusting or trusted or confiden* or unconfiden*)).ab,kf.

74 (life experience* or lived experience*1 or actual experience* or real experience*1).ti,ab,kf.

75 or/59-74

76 18 and 58 and 75

77 (kidney or renal or nephropath* or dialysis or predialysis or hemodialysis or haemodialysis or hemofiltration or haemofiltration or hemodiafiltration or haemodiafiltration or CKF or CKD or CRF or CRD or ESKD or ESRD or ESKF or ESRF or CAPD or CCPD or APD).ti. (419253)

78 qualitativ*.ti. or qualitative research/

79 ((patient* or client* or user* or consumer*1 or personal or carer* or caregiver* or care-giver* or family* or families) and experiences).ti.

80 ((patient* or client* or user* or consumer* or personal or carer* or caregiver* or care-giver* or family* or families) adj2 experienc*).ti.

81 77 and (78 or 79 or 80)

82 76 or 81

83 exp animals/ not humans/

84 (news or comment or editorial or letter or case reports or randomized controlled trial).pt.

85 case report.ti.

86 82 not (83 or 84 or 85)

87 limit 86 to (english spanish portuguese language and yr="2000 -Current")

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Checklist

www.prisma-statement.org

You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Section/Topic	Item No.	Checklist item	Reported on Page No.
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5, table 1
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	appendix1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6

Section/Topic	Item No.	Checklist item	Reported on Page No.
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	NA
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	NA
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7 and Fig 2
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	NA
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 2.
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	NA
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	NA
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	18
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	22
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	22 ss
FUNDING			

Section/Topic	Item No.	Checklist item	Reported on Page No.
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	24

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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BMJ Open

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

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Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Renal medicine, Sociology
Keywords:	Treatment burden, Chronic kidney disease, Systematic review, Haemodialysis, Kidney transplant

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 team[246], 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

Ethics approval and consent to participate

Not applicable

Consent to publish

Not applicable

Availability of data and material

EXPERTS1 Protocol is published in BMJ Open, with open access

May CR, Masters J, Welch L, Hunt K, Pope C, Myall M, Griffiths P, Roderick P, Glanville J, Richardson A: **EXPERTS 1—experiences of long-term life-limiting conditions among patients and carers: protocol for a qualitative meta-synthesis and conceptual modelling study**. *BMJ Open* 2015, **5**(4):e007372.

Meta-review of systematic reviews is published in BMJ Open, with open access

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
Aasen[107]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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
Boaz[175]	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-Ashurst[121]	2011	United Kingdom	London	20		CKD	Focus groups, vignettes and diaries	Thematic
Browne [226]	2016	United States	South	40		ESKD	Focus groups	Content
Buldukoglu[186]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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-Matoka[83]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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-John[90]	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
Ghadami[239]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Goldane[176]	2011	United States	1 C	39		Transplanted	Focus groups and interviews	Iterative analysis
Gordon[180]	2007	United States		20		Transplanted	Diary entries	Thematic
Gordon[84]	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
Haspeslagh[240]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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
Kierans[125]	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-Boothby[147]	2004	United Kingdom	1 H, 4 C	16		ESKD	Interviews	Thematic
Krespi-Boothby[151]	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
Landreneau[278]	2007	United States	2 C, South	12		ESKD	Interviews	Colaizzi's method

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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
Leung[181]	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-Vargas[94]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Martin-McDonald[194]	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-Martínez[48]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Nobahar [68]	2016	Iran	1 H, Semnan	8	12	ESKD	Interviews	Granheim and Lundman's approach
Noble[293]	2009	United Kingdom	1 service, London	30	17	ESKD	Interviews	Constant comparison
Noble[98]	2010	United Kingdom	1 service, London	30	17	ESKD	Interviews	Constant comparison
Noble[97]	2012	United Kingdom	1 service		19	ESKD	Interviews	Constant comparison
Nygardh[289]	2011	Sweden	1 C, South		12	CKD (Pre-dialysis)	Interviews	Content
Nygardh[236]	2011	Sweden	1 C, South	20		CKD	Interviews	Latent Content
Malheiro Oliveira[209]	2012	Brazil	Bahia	19		ESKD	Interviews	Categorical
Orr[182]	2007	United Kingdom	1 C	26		Transplanted	Focus groups	Thematic
Orr[183]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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
Ros[244]	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
Russell[241]	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
Schipper[184]	2014	The Netherlands	5 H	30		Transplanted	Focus groups and interviews	Thematic

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Schmid-Mohler[85]	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
Sheu[245]	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
Spiers[177]	2015	United Kingdom	1 C, London	4		Transplanted	Interviews	Interpretative phenomenological
Spiers [171]	2016	United Kingdom	2 online groups	10		ESKD	Interviews	Thematic
Stanfill[178]	2012	United States	1 C, mid-South	7		Transplanted	Focus groups	Iterative
Stewart [81]	2012	United States	2 C, urban	19		ESKD	Interviews	Coding
Tanyi[201]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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
Tielen[179]	2011	The Netherlands	1 C	26		Transplanted	Interviews	Q methodology
Tijerina[76]	2006	United States	8 C, Texas	26		ESKD	Interviews	Coding
Tong[63]	2009	Australia	4 H, Brisbane, Sydney, Melbourne	63		CKD/ESKD	Focus groups	Thematic
Tong[152]	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
Urstad[242]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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
Wiederhold[185]	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

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
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-Uhlin[132]	2016	Sweden	1 H, Southeast	8		ESKD	Interviews	Content
Yodchai [249]	2016	Thailand	2 H, Songkhla	20		ESKD	Interviews	Qualitative
Yodchai[199]	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 uncertainty[83 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	+

Challenge	Group of patient mostly affected	Type of country mostly affected	Severity
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.

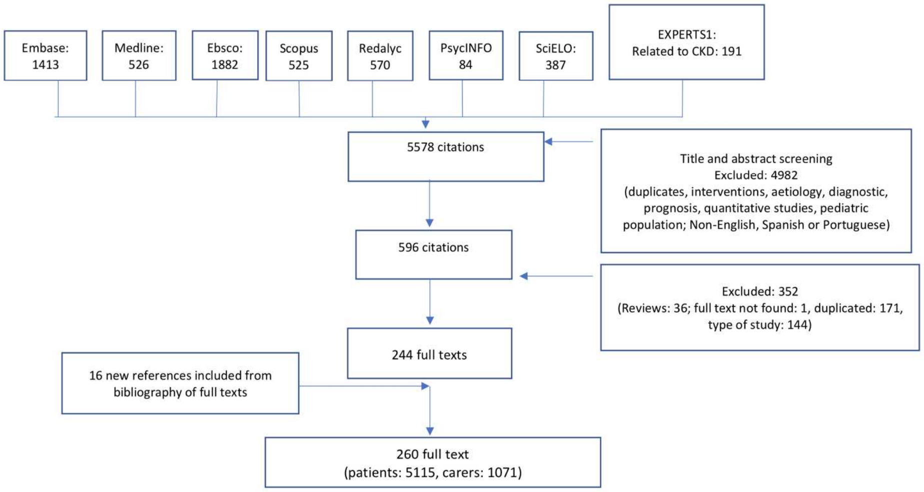

Figure 1. PRISMA flow chart of screening and selection process

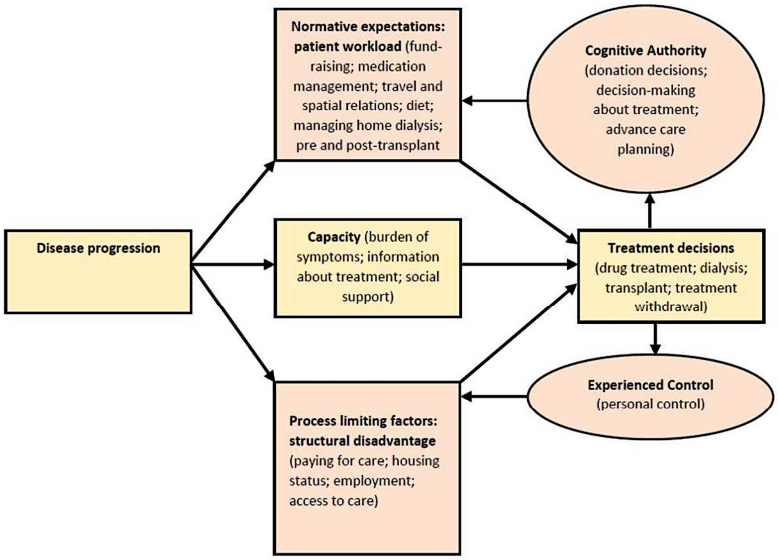

Figure 2. Thematic schema of experienced control and cognitive authority in CKD.

Appendix 1. Search strategy

1 exp Renal Insufficiency, Chronic/
2 Renal Insufficiency/
3 exp Renal Replacement Therapy/
4 Hemodialysis Units, Hospital/
5 (chronic kidney or chronic renal or chronic nephropath*).ti,ab,kf.
6 (kidney failure*1 or renal failure*1).ti,ab,kf.
7 (renal insufficienc* or kidney insufficienc*).ti,ab,kf.
8 (dialysis or predialysis).ti,ab,kf.
9 (hemodialysis or haemodialysis).ti,ab,kf.
10 (hemofiltration or haemofiltration).ti,ab,kf.
11 (hemodiafiltration or haemodiafiltration).ti,ab,kf.
12 (end-stage renal or end-stage kidney or endstage renal or endstage kidney).ti,ab,kf.
13 (stage 5 and (renal disease*1 or kidney disease*1)).ti,ab,kf.
14 (kidney transplant* or renal transplant* or kidney graft* or renal graft* or kidney replacement*1 or renal replacement*1).ti,ab,kf.
15 (CKF or CKD or CRF or CRD).ti,ab,kf.
16 (ESKD or ESRD or ESKF or ESRF).ti,ab,kf.
17 (CAPD or CCPD or APD).ti,ab,kf.
18 or/1-17
19 exp qualitative research/
20 qualitativ*.ti,ab,kf.
21 interviews as topic/
22 interview*.ti,ab,kf.
23 focus groups/
24 focus group*1.ti,ab,kf.
25 grounded theory/ or (grounded theor* or grounded study or grounded studies or grounded research or grounded analys*).ti,ab,kf.
26 phenomenol*.ti,ab,kf.
27 (ethnograph* or ethnonurs* or ethno-graph* or ethno-nurs*).ti,ab,kf.
28 (story or stories or storytelling or narrative*1 or narration*1).ti,ab,kf.
29 (open-ended or open question* or text*).ti,ab,kf.
30 Narration/ or personal narratives/ or personal narratives as topic/
31 (discourse* analys* or discurs* analys*).ti,ab,kf.
32 content* analys*.ti,ab,kf.
33 ethnological.ti,ab,kf.
34 purposive sampl*.ti,ab,kf.
35 (constant comparative or constant comparison*1).ti,ab,kf.
36 theoretical sampl*.ti,ab,kf.
37 (theme* or thematic*).ti,ab,kf.
38 (emic or etic or hermeneutic* or heuristic* or semiotic*).ti,ab,kf.
39 data saturat*.ti,ab,kf.
40 participant observ*.ti,ab,kf.

41 exp Humanism/ or (humanistic* or existential* or experiential* or paradigm*).ti,ab,kf.

42 Postmodernism/ or (social construct* or postmodern* or post-modern* or poststructural* or post-structural* or feminis* or constructivis*).ti,ab,kf.

43 (action research or cooperative inquir* or co-operative inquir*).ti,ab,kf.

44 human science.ti,ab,kf.

45 biographical method*.ti,ab,kf.

46 life world.ti,ab,kf.

47 theoretical saturation.ti,ab,kf.

48 group discussion*1.ti,ab,kf.

49 direct observation*.ti,ab,kf.

50 mixed method*.ti,ab,kf.

51 (observational method* or observational approach*).ti,ab,kf.

52 key informant*1.ti,ab,kf.

53 (field study or field studies or field research* or field work* or fieldwork*).ti,ab,kf.

54 (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kf.

55 "face-to-face".ti,ab,kf.

56 ((guide or structured) adj5 (discussion*1 or questionnaire*1)).ti,ab,kf.

57 (heidegger* or colaizzi* or speigelberg* or van manen* or van kaam* or merleau ponty* or husserl* or giorgi* or foucault* or corbin* or glaser*).ti,ab,kf.

58 or/19-57

59 Consumer Behavior/

60 attitude/ or exp attitude to health/ or Attitude to Death/

61 personal satisfaction/

62 exp Emotions/

63 Stress, psychological/

64 exp Patients/px

65 Caregivers/px

66 professional-patient relations/ or nurse-patient relations/ or physician-patient relations/

67 professional-family relations/

68 Empathy/

69 Feedback/

70 ((patient*1 or client*1 or user*1 or consumer*1 or personal or carer*1 or caregiver*1 or care-giver* or family*1 or families) and (experienc* or perspective*1 or perception*1 or opinion*1 or account or accounts or attitude*1 or view or views or viewpoint*1 or satisf* or unsatisf* or dissatisf* or disatisf* or belief*1 or believ*)).ti.

71 ((patient*1 or client*1 or user*1 or consumer*1 or personal or carer*1 or caregiver*1 or care-giver* or family*1 or families) adj3 (experienc* or perspective*1 or perception*1 or opinion*1 or account or accounts or attitude*1 or view or views or viewpoint*1 or satisf* or unsatisf* or dissatisf* or disatisf* or belief*1 or believ*)).ab,kf.

72 ((patient*1 or client*1 or user*1 or consumer*1 or personal or carer*1 or caregiver*1 or care-giver* or family*1 or families) and (emotion* or feeling*1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet* or anxious* or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat* or stress* or distress* or embarrass* or empath* or accept* or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother* or unbother* or pleased or displeased* or concern* or burden* or hassl* or convenien* or

inconvenien* or confus* or hope or hopeless or hopeful or trust or trusts or mistrust* or distrust* or entrust* or trusting or trusted or confiden* or unconfiden*)).ti.

73 ((patient* or client* or user* or consumer* or personal or carer* or caregiver* or care-giver* or family* or families) adj3 (emotion* or feeling* or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet* or anxious* or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrate* or stress* or distress* or embarrass* or empath* or accept* or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother* or unbother* or pleased or displeased* or concern* or burden* or hassl* or convenien* or inconvenien* or confus* or hope or hopeless or hopeful or trust or trusts or mistrust* or distrust* or entrust* or trusting or trusted or confiden* or unconfiden*)).ab,kf.

74 (life experience* or lived experience*1 or actual experience* or real experience*1).ti,ab,kf.

75 or/59-74

76 18 and 58 and 75

77 (kidney or renal or nephropath* or dialysis or predialysis or hemodialysis or haemodialysis or hemofiltration or haemofiltration or hemodiafiltration or haemodiafiltration or CKF or CKD or CRF or CRD or ESKD or ESRD or ESKF or ESRF or CAPD or CCPD or APD).ti. (419253)

78 qualitativ*.ti. or qualitative research/

79 ((patient* or client* or user* or consumer*1 or personal or carer* or caregiver* or care-giver* or family* or families) and experiences).ti.

80 ((patient* or client* or user* or consumer* or personal or carer* or caregiver* or care-giver* or family* or families) adj2 experienc*).ti.

81 77 and (78 or 79 or 80)

82 76 or 81

83 exp animals/ not humans/

84 (news or comment or editorial or letter or case reports or randomized controlled trial).pt.

85 case report.ti.

86 82 not (83 or 84 or 85)

87 limit 86 to (english spanish portuguese language and yr="2000 -Current")

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Checklist

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You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Section/Topic	Item No.	Checklist item	Reported on Page No.
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5 and table 1
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	appendix1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6, 7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6, 7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5, Table 1, 2.
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6

Section/Topic	Item No.	Checklist item	Reported on Page No.
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	NA
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	NA
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7 and Fig 2
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	NA
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 2.
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	NA
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	NA
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	18
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	22
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	22 ss
FUNDING			

Section/Topic	Item No.	Checklist item	Reported on Page No.
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	24

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