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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 EXPERTS1 Protocol, PROSPERO registration number: 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, Scientific Electronic Library Online and Red de Revistas Científicas de América Latina y el Caribe, España y Portugal. Content was analysed with theoretical framework using middle-range theories.

Results Searches resulted in 260 studies from 30 countries (5115 patients and 1071 carers). Socioeconomic 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 uninsurance or underinsurance. 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 uninsured or underinsured 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.

PROSPERO registration number CRD42014014547.

Strengths and limitations of this study

- We analysed data with a coding framework supported by middle-range theories to understand the work involved in being a person with chronic kidney disease.
- 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.

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, hospitalisation, 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-income 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] Patients' 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 underinsured 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 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 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 onwards was established to include current treatments.

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.

CKD, chronic kidney disease; PICO, participants, interventions, comparators and outcomes.

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 Scientific Electronic Library Online and 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 supplementary 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 Programme 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 are shown in table 2. Manuscripts were entered into Atlas.Ti V.7.5.12 (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

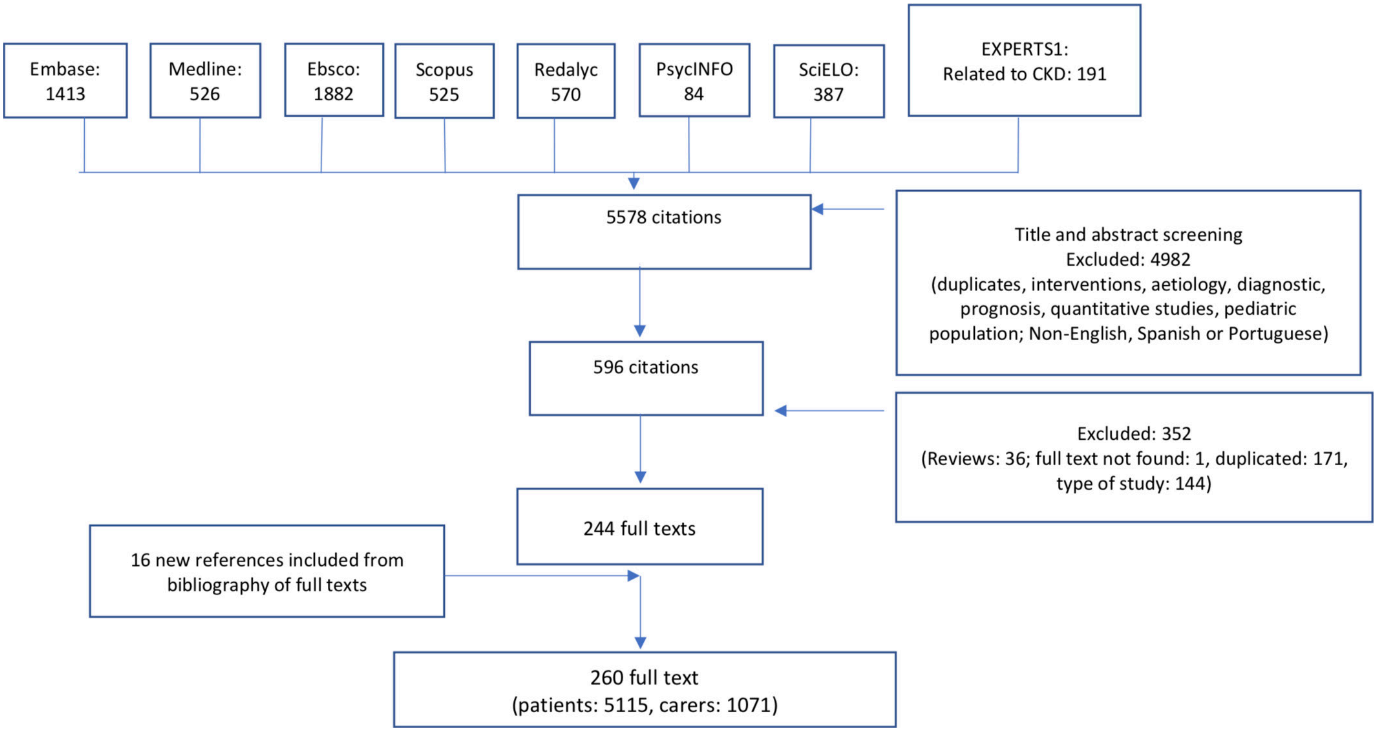

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart of screening and selection process. CKD, chronic kidney disease.

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: the USA with 52 (20%), the UK 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, box 1 shows illustrative quotations, table 3 shows summary of results and table 4 shows main challenges related to BoT.

Structural inequalities

Access to care

Poverty and other socioeconomic 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 recognised fragmentation and lack of integration as important problems.[40 45 48–51] Where government or private insurance coverage of ESKD treatment was limited, for example, Mexico or India, patients paid for some or all the following: vascular access, hospitalisation, 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

Table 2 Characteristics of included studies

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Aasen *et al*[107]	2012	Norway	5 H, East, West	11		ESKD	Interviews	Critical discourse
Aasen *et al*[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	USA	1 C, Southwest	80		ESKD	Interviews	Naturalistic inquiry, thematic
Allen *et al*[173]	2011	Canada	1 H, urban	7		ESKD	Ethnographic observations, interviews	Participatory action, thematic
Allen *et al*[64]	2015	Canada	2 H	6	11	ESKD	Ethnographic observations, interviews	Thematic
Anderson *et al*[77]	2008	Australia	9 H, 17 C	241		ESKD	Interviews	Thematic
Anderson *et al*[53]	2012	Australia	9 H, 17 C	241		ESKD	Interviews	Thematic
Arslan and Ege[200]	2009	Turkey	1 H, Kenya	10		ESKD	Interviews	Content
Ashby *et al*[38]	2005	Australia	2 H, Melbourne	16		ESKD	Interviews	Grounded theory
Avril-Sephula *et al*[118]	2014	UK	1 H, North	8		ESKD	Interviews	Thematic
Axelsson *et al*[187]	2012	Sweden	2 H, 2 C	8		ESKD	Interviews	Phenomenological, hermeneutical
Axelsson *et al*[136]	2012	Sweden	2 H, 2 C	8		ESKD	Interviews	Phenomenological, hermeneutical
Axelsson *et al*[134]	2015	Sweden	2 H, 1 C, urban		14	ESKD	Interviews	Content
Bailey *et al*[235]	2015	UK	Bristol	32		Transplanted	Interviews	Constant comparison
Bailey *et al*[39]	2016	UK	Bristol	13		Transplanted	Interviews	Constant comparison
Baillie and Lankshear[156]	2015	UK	Wales	16	9	ESKD	Interviews	Thematic
Baillie and Lankshear[157]	2015	UK	Wales	16	9	ESKD	Interviews	Thematic
Barbosa and Valadares[145]	2009	Brazil	1 C, Rio de Janeiro	10		ESKD	Interviews	Grounded theory
Bath *et al*[252]	2003	UK	South	10		ESKD	Interviews	Phenomenological
Beanlands *et al*[210]	2005	Canada	Ontario		37	ESKD	Interviews	Grounded theory
Bennett *et al*[197]	2013	Australia	4 C	9	2	ESKD	Interviews facilitated by images	Thematic
Blogg and Hyde[69]	2008	Australia	Urban		5	ESKD	Interviews	Ethnographic
Boaz and Morgan[175]	2014	UK	Rural, urban	25		Transplanted	Interviews	Constant comparison
Bourbonnais and Tousignant[105]	2012	Canada	1 H	25		ESKD	Interviews	Content

Continued

Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Bridger[238]	2009	UK	GP, South	23		CKD	Interviews, drawings, journals	Grounded theory
Bristowe *et al*[126]	2015	UK	2 C, London	20		ESKD	Interviews	Thematic
de Brito-Ashurst *et al*[121]	2011	UK	London	20		CKD	Focus groups, vignettes and diaries	Thematic
Browne *et al*[226]	2016	USA	South	40		ESKD	Focus groups	Content
Buldukoglu *et al*[186]	2005	Turkey	Antalya	40		Transplanted	Open-ended questions	Constant comparison
Burnette and Kickett[78]	2009	Australia	1 C, Perth	6		ESKD	Interviews	Thematic
Cadena *et al*[154]	2015	Mexico	Coyotepec, Mexico	5		ESKD	Interviews	Interpretative phenomenological
Calvey and Mee[146]	2011	Ireland	NA	7		ESKD	Interviews	Colaizzi's method
Calvin[251]	2004	USA	3 C, Texas	12		ESKD	Interviews	Constant comparison
Calvin *et al*[292]	2014	USA	Texas		18	ESKD	Interviews	Interpretative, Glaserian
Campos and Turato[234]	2003	Brazil	1 H, Sao Paulo	7		ESKD	Interviews	Thematic
Campos and Turato[87]	2010	Brazil	1 H, Sao Paulo	7		ESKD	Interviews	Thematic
Campos *et al*[88]	2015	Brazil	H, C, Paraná	23		ESKD	Interviews	Content
Cases *et al*[279]	2011	UK	NA	6		ESKD	Interviews	Phenomenological
Cervantes *et al*[52]	2017	USA	1 H, Colorado	20		ESKD	Interviews	Thematic
Chatrung *et al*[188]	2015	USA	California	8		CKD	Interviews	Thematic
Chenitz *et al*[86]	2014	USA	4 C, Pennsylvania	30		ESKD	Interviews	Grounded theory
Chiaranai[40]	2016	Thailand	1 H	26		ESKD	Interviews	Thematic
Cho and Shin[41]	2016	South Korea	1 H, South	5		ESKD	Interviews	Colaizzi's method
Chong *et al*[164]	2016	South Korea	1 H, South	8		ESKD	Interviews	Content
Clarkson and Robinson[106]	2010	USA	Oklahoma	10		ESKD	Interviews	Thematic
Costa *et al*[198]	2014	Brazil	3 H, Paraíba	26		ESKD	Interviews	Lexical
Costantini *et al*[92]	2008	Canada	Ontario	14		CKD	Interviews	Content
Cox *et al*[148]	2016	USA	6 C, New Mexico	50		ESKD	Interviews	Interpretive description
Cramm *et al*[219]	2015	The Netherlands	1 H, Rotterdam	15	12	ESKD	Interviews	Factor analysis, Q methodology
Cristóvao *et al*[113]	2013	Portugal	1 C, Lisbon	20		ESKD	Interviews	Thematic
Crowley-Matoka *et al*[83]	2005	Mexico	2 prog, Guadalajara	50		Transplanted	Interviews	NA
Curtin *et al*[265]	2001	USA	Diverse	18		ESKD	Interviews	Content

Continued

Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Curtin *et al*[264]	2002	USA		18		ESKD	Interviews	Content
da Silva *et al*[103]	2016	Brazil	1 C, Northeast	30		ESKD	Interviews	Content and thematic
da Silva *et al*[338]	2011	Brazil	1 H, Rio Grande do Sul	9		ESKD	Interviews	Qualitative
Darrell *et al*[281]	2016	USA	1 H	12		ESKD	Interviews	Giorgi's method
Davison *et al*[231]	2006	Canada	Alberta	24		ESKD	Interviews	Constant comparison, iterative
Davison *et al*[291]	2006	Canada	1 H	19		ESKD	Interviews	inductive
de Brito *et al*[89]	2015	Brazil	1 H, Minas Gerais	50		Transplanted	Interviews	Collective subject technique
de Rosenroll *et al*[277]	2013	Canada	1 H		10	ESKD	Interviews	Constant comparison
Dekkers *et al*[42]	2005	The Netherlands	2 C	7		ESKD	Interviews	Phenomenological
DePasquale *et al*[221]	2013	USA	NP, 1 C	68	62	CKD	Group interviews	Mixed method
dos Reis *et al*[155]	2008	Brazil	1 H, Sao Paulo	8		ESKD	Interviews	Content
dos Santos *et al*[162]	2011	Brazil	Rio de Janeiro	8		ESKD	Interviews	Grounded theory
dos Santos *et al*[259]	2015	Brazil	3 NP, Rio Grande do Sul	20		Transplanted	Interviews	Critical incident
Ekelund *et al*[43]	2010	Sweden	1 C, South	39	21	ESKD	Interviews	Content
Erlang *et al*[203]	2015	Denmark	1 H	9		CKD (predialysis)	Interviews	Systematic text condensation
Eslami *et al*[214]	2016	Iran	4 C, Isfahan		20	ESKD	Interviews	Thematic
Finnegan-John *et al*[90]	2013	UK	1 trust, London	118	12	CKD/ESKD	Interviews and focus groups	Thematic
Flores *et al*[165]	2004	Brazil	1 H, Rio Grande do Sul	9		ESKD	Interviews	Content
Fraguas *et al*[37]	2008	Brazil	2 H, Minas Gerais		18	ESKD	Interviews	Content
Ghadami *et al*[239]	2012	Iran	1 charity, Isfahan	15		Transplanted	Interviews	Content
Giles *et al*[159]	2003	Canada	1 H, urban	4		ESKD	Interviews	Thematic
Giles *et al*[160]	2005	Canada		4		ESKD	Interviews	Phenomenological
Goff *et al*[288]	2015	USA	New Mexico	13	9	ESKD	Interviews	Thematic
Goldane *et al*[176]	2011	USA	1 C	39		Transplanted	Focus groups and interviews	Iterative analysis
Gordon *et al*[180]	2007	USA		20		Transplanted	Diary entries	Thematic
Gordon *et al*[84]	2009	USA	2 H, Illinois, New York	82		Transplanted	Interviews	Thematic
Gricio *et al*[114]	2009	Brazil	1 H, Sao Paulo	20		ESKD	Interviews	Thematic

Continued

Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Gullick *et al*[339]	2016	Australia	1 H, Sydney	11	5	ESKD	Interviews	Hermeneutic interpretation
Hagren *et al*[282]	2001	Sweden	1 H	15		ESKD	Interviews	Content
Hagren *et al*[115]	2005	Sweden	3 H	41		ESKD	Interviews	Content
Hain *et al*[189]	2011	USA	6 C, Southeast	56		ESKD	Interviews	Story inquiry method
Hanson *et al*[70]	2016	Australia	1 C, West	20		ESKD	Interviews	Thematic
Harrington *et al*[283]	2016	UK	8 H	24		Transplanted	Interviews	Thematic
Harwood *et al*[270]	2014	Canada	1 H	13		ESKD	Interviews	Content
Harwood *et al*[248]	2005	UK	1 H, London	11		CKD/ESKD	Interviews	Content
Haspeslagh *et al*[240]	2013	Belgium	1 H, Leuven	31		Transplanted	Interviews and questionnaires	Thematic
Heiwe *et al*[137]	2003	Sweden	1 H, Karolinska	16		ESKD	Interviews	Contextual
Heiwe *et al*[140]	2004	Sweden	1 H, Karolinska	16		CKD/ESKD	Interviews	Contextual
Herbias *et al*[116]	2016	Chile	1 C, Santiago	12		ESKD	Interviews	Streubert's method
Herlin *et al*[284]	2010	Sweden	3 C	9		ESKD	Interviews	Giorgi's method
Hollingdale *et al*[227]	2008	UK		20		CKD/ESKD	Focus groups	Framework approach
Hong *et al*[120]	2017	Singapore	1 H	14		ESKD	Interviews	Thematic
Horigan *et al*[138]	2013	USA	1 C, Mid-Atlantic	14		ESKD	Interviews	Content
Hutchison *et al*[290]	2017	Canada	1 clinic, urban	9	16	CKD/ESKD	Interviews	Interpretive description
Iles-Smith *et al*[232]	2005	UK	1 C, Manchester	10		CKD (predialysis)	Interviews	Thematic
Johnston *et al*[128]	2012	UK	1 trust, London	9		ESKD	Interviews	Thematic
Kaba *et al*[340]	2007	Greece	2 H, Athens	23		ESKD	Interviews	Qualitative
Kahn *et al*[35]	2015	USA	2 NP, New York	34		CKD	Interviews	Thematic
Karamanidou *et al*[15]	2014	UK	1 C, London	7		ESKD	Interviews	Interpretative, phenomenological
Kazley *et al*[44]	2015	USA	1 C, Southeast	20		CKD/ESKD	Focus groups	Thematic
Keeping *et al*[73]	2001	Canada	East	8		ESKD	Interviews	Thematic
Kierans *et al*[167]	2001	Ireland		5		ESKD	Interviews, life stories	Phenomenological
Kierans *et al*[166]	2005	Ireland		5		CKD/ESKD	Interviews	Phenomenological
Kierans *et al*[125]	2013	Mexico	1 H, Jalisco	51	87	CKD/ESKD, transplanted	Interviews, observation*	Ethnographic approach
King *et al*[91]	2002	UK	1 C	22		CKD/ESKD	Interviews	Template approach
Knihs *et al*[168]	2013	Brazil	1 C, South	20		ESKD	Interviews	Content
Krespi-Boothby *et al*[147]	2004	UK	1 H, 4 C	16		ESKD	Interviews	Thematic

Continued

Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Krespi-Boothby *et al*[151]	2013	UK	1 H, 4 C	16		ESKD	Interviews	Template approach
Ladin *et al*[202]	2016	USA	2 C, Massachusetts	23		ESKD	Interviews	Thematic
Ladin *et al*[269]	2017	USA	2 C, Massachusetts	31		ESKD	Interviews	Thematic Nutbeam's framework
Landreneau *et al*[274]	2006	USA	1 C, 1 NP, South	6		ESKD	Interviews	Colaizzi's method
Landreneau *et al*[278]	2007	USA	2 C, South	12		ESKD	Interviews	Colaizzi's method
Lawrence *et al*[169]	2013	UK	1 C	10		ESKD	Interviews	Conceptual and categorical
Lederer *et al*[266]	2015	USA	1 C	32		CKD/ESKD	Interviews	Thematic
Lee *et al*[223]	2008	Denmark	Diverse	27	18	ESKD	Focus groups	Thematic
Lee *et al*[45]	2016	Singapore	1 organisation		20	ESKD	Interviews	Thematic
Lenci *et al*[256]	2012	USA		4		ESKD	Interviews	Thematic
Leung *et al*[181]	2007	Hong Kong	1 C	12		Transplanted	Interviews	Content
Lewis *et al*[285]	2015	UK	14 H	40		ESKD	Interviews	Grounded theory
Lin *et al*[190]	2015	Taiwan	1 C, S, rural	15		ESKD	Interviews	Constant comparison
Lindberg *et al*[46]	2008	Sweden	1 C, mid-country	10		ESKD	Interviews	Content
Lindberg *et al*[262]	2013	Sweden	1 C, mid-country	10		ESKD	Interviews	Content
Lindsay *et al*[280]	2014	Australia	1 C, Sydney	7		ESKD	Interviews	Thematic
Llewellyn *et al*[271]	2014	UK	4 C, London	19		ESKD	Interviews	Thematic
Lo *et al*[129]	2016	Australia	4 H, Melbourne, Sydney	58		CKD/ESKD	Interviews and focus groups	Thematic
Lopes *et al*[170]	2014	Brazil	1 C, Santa Catarina	12		ESKD	Interviews	Interpretative
Lopez-Vargas *et al*[94]	2014	Australia	3 C, New South Wales	38		CKD	Focus groups	Thematic
Lopez-Vargas *et al*[93]	2016	Australia	3 C, New South Wales	38		CKD/ESKD	Focus groups	Thematic
Lovink *et al*[217]	2015	The Netherlands	1 C	12		ESKD	Interviews	Content
Low *et al*[161]	2014	UK	5 C, Southeast		26	ESKD	Interviews	Thematic
Machado *et al*[149]	2003	Brazil	Sao Paulo	18		ESKD	Interviews	Discourse
Marques *et al*[228]	2014	Brazil	Paraná		10	ESKD	Interviews	Content
Martin-McDonald *et al*[194]	2003	Australia	5 C	10		ESKD	Interviews	Thematic
Martin-McDonald *et al*[195]	2003	Australia	1 C	10		ESKD	Interviews	Thematic
Mason *et al*[95]	2007	UK	1 C	9	5	CKD	Focus groups	Framework approach
McCarthy *et al*[163]	2010	Australia	1 H	5		ESKD	Interviews	Sequential

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Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
McKillop *et al*[267]	2013	UK	Clinics	10		CKD	Interviews	Thematic
Mercado-Martínez *et al*[49]	2014	Mexico	Jalisco, San Luis Potosí	21		Transplanted	Interviews	Thematic
Mercado-Martínez *et al*[48]	2015	Brazil	1 H, South	11	5	ESKD	Interviews	Content
Mercado-Martínez *et al*[47]	2015	Mexico	Public H and institutions, Jalisco	37	50	ESKD	Interviews	Content
Mitchell *et al*[205]	2009	UK	1 C	10		CKD/ESKD	Interviews	Content
Molzahn *et al*[294]	2012	Canada	Middle size city	14		CKD	Interviews	Thematic
Moran *et al*[204]	2009	Ireland	1 H	16		ESKD	Interviews	Interpretive
Moran *et al*[150]	2009	Ireland	1 H	16		ESKD	Interviews	Interpretive
Moran *et al*[133]	2011	Ireland	H	16		ESKD	Interviews	Interpretative
Morton *et al*[79]	2010	Australia	Diverse	95		ESKD	Interviews	Thematic
Muduma *et al*[96]	2016	UK	2 C	37		Transplanted	Focus groups	Qualitative
Nagpal *et al*[218]	2017	USA	1 C, New York	36		ESKD	Interviews	Coding
Namiki *et al*[220]	2010	Australia	1 H	4		ESKD	Interviews	Thematic
Niu *et al*[196]	2017	China	1 C, Jiangsu	23		ESKD	Interviews	Continuous comparison
Nobahar *et al*[67]	2016	Iran	1 H, Semnan	8	12	ESKD	Interviews	Graneheim Lundman content
Nobahar *et al*[68]	2016	Iran	1 H, Semnan	8	12	ESKD	Interviews	Granheim and Lundman's approach
Noble *et al*[293]	2009	UK	1 service, London	30	17	ESKD	Interviews	Constant comparison
Noble *et al*[98]	2010	UK	1 service, London	30	17	ESKD	Interviews	Constant comparison
Noble *et al*[97]	2012	UK	1 service		19	ESKD	Interviews	Constant comparison
Nygardh *et al*[289]	2011	Sweden	1 C, South		12	CKD (predialysis)	Interviews	Content
Nygardh *et al*[236]	2011	Sweden	1 C, South	20		CKD	Interviews	Latent content
Malheiro Oliveira *et al*[209]	2012	Brazil	Bahia	19		ESKD	Interviews	Categorical
Orr *et al*[182]	2007	UK	1 C	26		Transplanted	Focus groups	Thematic
Orr *et al*[183]	2007	UK	1 C	26		Transplanted	Focus groups	Thematic
Oyegbile *et al*[65]	2016	Nigeria	2 H, Southwest		15	ESKD	Interviews	Content
Pelletier-Hibbert *et al*[286]	2001	Canada	East		41	ESKD	Focus groups	Thematic
Piccoli *et al*[224]	2010	Italy	1 H	12		CKD/ESKD, transplanted	Focus groups	Not clear
Pietrovski *et al*[208]	2006	Brazil	1 H, Paraná	15		ESKD	Interviews	Content
Pilger *et al*[225]	2010	Brazil	1 C, Paraná	22		ESKD	Interviews	Thematic

Continued

Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Polaschek *et al*[54]	2003	New Zealand	1 C	6		ESKD	Interviews	Thematic
Polaschek *et al*[55]	2006	New Zealand	1 regional department	20		ESKD	Interviews	Thematic
Polaschek *et al*[56]	2007	New Zealand	1 regional department	20		ESKD	Interviews	Thematic
Prieto *et al*[130]	2011	Spain	Andalusia	22		ESKD	Interviews	Discourse
Rabiei *et al*[141]	2015	Iran	Isfahan		20	ESKD	Interviews	Thematic
Ravenscroft *et al*[260]	2005	Canada	3 C	7		ESKD	Interviews	Inductive
Reid *et al*[268]	2012	UK	1 C, clinics	11		CKD/ESKD	Interviews	Thematic
Reta *et al*[131]	2014	Spain	1 H, Araba	14		ESKD	Interviews	Content
Richard *et al*[108]	2010	USA		14		ESKD	Interviews	Cultural negotiation model framework
Rifkin *et al*[99]	2010	USA	1 C	20		CKD/ESKD	Interviews	Thematic
Rix *et al*[58]	2014	Australia	New South Wales, rural	18		ESKD	Interviews	Thematic
Rix *et al*[57]	2015	Australia	New South Wales, rural	18	29	ESKD	Interviews	Thematic
Rodrigues *et al*[191]	2011	Brazil	1 C, South	8		ESKD	Interviews	Categorical
Ros *et al*[244]	2012	USA	1 H, Maryland	19		ESKD	Focus groups	Thematic
Roso *et al*[119]	2013	Brazil	1 H, South	15		ESKD	Narrative interviews	Thematic
Russ *et al*[229]	2005	USA	2 C, California	43		ESKD	Interviews	Anthropologic study
Russell *et al*[241]	2003	USA	1 C, Midwest	16		Transplanted	Interviews	Constant comparison
Rygh *et al*[71]	2012	Norway	North	11		ESKD	Interviews	Inductive, actor's point of view
Sadala *et al*[72]	2012	Brazil	1 H	19		ESKD	Narrative interviews	Phenomenological, hermeneutical
Sahaf *et al*[222]	2017	Iran	2 hour, Sari	9		ESKD	Interviews	van Manen's thematic
Salvalaggio *et al*[82]	2003	Canada	1 H, Ontario	12		ESKD	Interviews	Immersion/crystalisation
Schell *et al*[272]	2012	USA	1 university system, 1 NP, North Carolina	29	11	CKD/ESKD	Interviews and focus groups	Thematic
Schipper *et al*[184]	2014	The Netherlands	5 H	30		Transplanted	Focus groups and interviews	Thematic
Schmid-Mohler *et al*[85]	2014	Switzerland	1 H, Zurich	12		Transplanted	Interviews	Content
Schober *et al*[206]	2016	USA	14 states	48		ESKD	Interviews	Thematic
Seah *et al*[50]	2013	Singapore	3 H	9		ESKD	Interviews	Interpretative phenomenological

Continued

Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Shahgholian *et al*[142]	2015	Iran	1 H, Isfahan	17		ESKD	Interviews	Colaizzi's method
Shaw *et al*[275]	2015	New Zealand	Diverse	24		ESKD	Interviews	Phenomenological
Sheu *et al*[245]	2012	USA	Maryland	27	23	ESKD	Focus groups	Thematic
Shih *et al*[59]	2011	New Zealand	1 C, North	7		ESKD	Interviews	Hermeneutical and thematic
Shirazian *et al*[123]	2016	USA	1 C, Northeast	23		CKD	Focus groups	Thematic
Sieverdes *et al*[174]	2015	USA	1 C, South Carolina	27		Transplanted	Focus groups	Thematic
Smith *et al*[207]	2010	USA	2 C	19		ESKD	Focus groups	Content
Spiers *et al*[177]	2015	UK	1 C, London	4		Transplanted	Interviews	Interpretative phenomenological
Spiers *et al*[171]	2016	UK	2 online groups	10		ESKD	Interviews	Thematic
Stanfill *et al*[178]	2012	USA	1 C, mid-South	7		Transplanted	Focus groups	Iterative
Stewart *et al*[81]	2012	USA	2 C, urban	19		ESKD	Interviews	Coding
Tanyi *et al*[201]	2006	USA	Mid-West	16		ESKD	Interviews	Colaizzi's method
Tanyi *et al*[192]	2008	USA	2 C, mid-West	16		ESKD	Interviews	Colaizzi's method
Tanyi *et al*[193]	2008	USA	Mid-West	16		ESKD	Interviews	Colaizzi's method
Tavares *et al*[216]	2016	Brazil	1 H, Rio de Janeiro		19	ESKD	Interviews and groups	Content
Taylor *et al*[111]	2016	Australia	2 H, Sydney	26		ESKD	Interviews	Thematic
Taylor *et al*[215]	2015	UK	6 trusts	15	11	ESKD	Interviews	Constant comparison
Theofilou *et al*[122]	2013	Greece	1 H, Athens	10		ESKD	Interviews	Phenomenological
Thomé *et al*[247]	2011	Brazil	1H, Rio Grande do Sul		10	ESKD	Interviews	Cultural
Tielen *et al*[179]	2011	The Netherlands	1 C	26		Transplanted	Interviews	Q methodology
Tijerina *et al*[76]	2006	USA	8 C, Texas	26		ESKD	Interviews	Coding
Tong *et al*[63]	2009	Australia	4 H, Brisbane, Sydney, Melbourne	63		CKD/ESKD	Focus groups	Thematic
Tong *et al*[152]	2013	Italy	4 C, Bari, Marsala, Nissoria, Taranto	22	20	ESKD	Interviews	Thematic
Tong *et al*[237]	2015	Australia	1 C, Adelaide	15		CKD/ESKD	Interviews	Thematic
Tonkin-Crine *et al*[127]	2015	UK	9 C	42		ESKD	Interviews	Thematic
Torchi *et al*[153]	2014	Brazil	1 C, Rio de Janeiro	10		ESKD	Interviews	Collective subject technique
Tovazzi *et al*[117]	2012	Italy	North	12		ESKD	Interviews	Phenomenological
Tweed *et al*[109]	2005	UK	1 C, Leicester	9		ESKD	Interviews	Phenomenological

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Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Urstad *et al*[242]	2012	Norway	1 C	15		Transplanted	Interviews	Hermeneutic
Valsaraj *et al*[60]	2014	India	1 H, South Karnataka	10		ESKD	Interviews	Phenomenological
Velez *et al*[100]	2006	Spain	1 C	12		ESKD	Interviews	Thematic
Vestman *et al*[263]	2014	Sweden	1 H	9		ESKD	Written narratives	Thematic
Visser *et al*[276]	2009	The Netherlands	1 C	14		ESKD	Interviews	Thematic
Wachterman *et al*[172]	2015	USA	1 C	16		ESKD	Interviews	Thematic
Walker *et al*[124]	2012	UK	1 H	9		CKD	Interviews	Thematic
Walker *et al*[51]	2016	New Zealand	3 C	43	9	ESKD	Interviews	Thematic
Walker *et al*[61]	2016	New Zealand	3 C	43	9	ESKD	Interviews	Thematic
Walker *et al*[80]	2017	New Zealand	3 C	13		ESKD	Interviews	Thematic
Walton *et al*[258]	2002	USA	1 H, rural, Northwest	11		ESKD	Interviews	Grounded theory
Walton[257]	2007	USA	1 C	21		ESKD	Interviews	Grounded theory
Weil[253]	2000	USA	2 C, rural, Northwest	14		ESKD	Interviews	Thematic
Wells[254]	2015	USA	3 C, 1 NP, Texas	17	17	ESKD	Interviews	Thematic
Wells[62]	2015	USA	3 C, 1 NP, Texas	15	21	ESKD	Interviews	Thematic
White *et al*[139]	2004	USA	1 C, Colorado	6	9	ESKD	Interviews	Thematic
Wiederhold *et al*[185]	2012	Germany	1 C	10		Transplanted	Interviews	Content
Wilkinson *et al*[75]	2011	UK	Luton, West London, Leicester	48		ESKD	Interviews	Thematic
Wilkinson *et al*[233]	2014	UK	4 C	16	45	Transplanted	Interviews and focus groups	Thematic
Wilkinson *et al*[74]	2016	UK	4 C	16	45	ESKD	Interviews and focus groups	Thematic
Williams *et al*[101]	2009	Australia	2 H	20		CKD	Interviews	Qualitative
Williams *et al*[102]	2008	Australia	2 H, Melbourne	23		CKD	Interviews and focus groups	Interpretative
Williams *et al*[261]	2009	Australia	1 H, Melbourne	23		CKD	Interviews	Qualitative
Wilson *et al*[255]	2015	UK	3 C	15	15	ESKD	Focus groups	Thematic
Winterbottom *et al*[230]	2012	UK	1 C, Northern England	20		CKD	Interviews	Thematic
Wu *et al*[66]	2015	Taiwan	2 C, Central	15		ESKD	Interviews	Thematic

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Table 2 Continued

Author	Year	Country	Setting	Patients	Carers	Type of patient	Data collection	Data analysis reported
Xi *et al*[110]	2011	Canada	1 C, Ontario	13		ESKD	Interviews	Thematic
Xi *et al*[158]	2013	Canada	1 C, Ontario	10		ESKD	Interviews	Thematic
Yeun *et al*[143]	2016	South Korea	1 H, Seoul		33	ESKD	Interviews	Q methodology
Yngman-Uhlin *et al*[135]	2010	Sweden	Southeast	14		ESKD	Interviews	Phenomenological
Yngman-Uhlin *et al*[132]	2016	Sweden	1 H, Southeast	8		ESKD	Interviews	Content
Yodchai *et al*[249]	2016	Thailand	2 H, Songkhla	20		ESKD	Interviews	Qualitative
Yodchai *et al*[199]	2012	Thailand	1 C, South	5		ESKD	Interviews	Grounded theory
Yu *et al*[112]	2014	Singapore	NKF	32		ESKD	Interviews	Thematic
Yumang *et al*[144]	2009	Canada	1 H, Quebec	9		ESKD	Interviews	Colaizzi's method
Ziegert *et al*[213]	2001	Sweden			12	ESKD	Interviews	Pragmatic approach
Ziegert *et al*[211]	2006	Sweden	Southwest		13	ESKD	Interviews	Content
Ziegert *et al*[212]	2009	Sweden	Southwest		20	ESKD	Interviews	Content

*Includes healthcare staff.

C, centre, unit or clinic; CKD, chronic kidney disease; D, dialysis; ESKD, end-stage kidney disease; GP, general practice; H, hospital; HD, haemodialysis; NA, not available; NKF, National Kidney Foundation (Singapore); NP, nephrology practice; PD, peritoneal dialysis.

Box 1 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]

Continued

Box 1 Continued

Control and decision-making

I have free rein 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 the 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, aged 45 years, 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]

CKD, chronic kidney disease.

risk, whatever their treatment modality, as in the case of many undocumented and uninsured immigrants in the USA.[35 47–49 52 66] In countries with poor healthcare infrastructure, patients reported shortage of public specialised hospitals, long delays to undergo examinations, limited number of haemodialysis machines available, lack of ward space or poor bed conditions in hospitals, for example, 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 USA 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 with 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 stigmatised 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

Table 3 Summary of results

Qualitative analysis		
Primary category	**Secondary category**	**Summary results**
Structural disadvantage	*Access to care*	Socioeconomic 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 uninsured or underinsured.[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] Uninsured or underinsured 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 uninsurance or underinsurance 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 stigmatised as a sign of poverty.[121]
	Navigating healthcare 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, socioeconomically 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.[102,173]
	Negotiating costs and fund-raising	Fund-raising was important for those who were uninsured or underinsured, 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 uninsured or underinsured.[47,49,52,125,217,218]
	Travel and time management	Patients often travelled for long distances to dialysis centres, three 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]
	Pretransplant 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 organising 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]

Continued

Table 3 Continued

Qualitative analysis		
Primary category	**Secondary category**	**Summary results**
	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 healthcare 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, healthcare 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, healthcare 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 hours 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 emphasised importance of respecting patients' wishes.[202 233 292]

CKD, chronic kidney disease.

Table 4 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 uninsured or underinsured.	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 uninsured or underinsured.	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 uninsured or underinsured.	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 uninsurance or underinsurance 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, three times a week.	ESKD	HIC, LMIC	++
Home dialysis patients had to pay transport to training, appointments and other check-ups.	ESKD	HIC, LMIC	++
Patients arranged daily activities between sessions.	ESKD	HIC, LMIC	+
For home dialysis, training was required with extended periods off work.	ESKD	HIC, LMIC	+
For home dialysis, homes needed physical adaptation.	ESKD	HIC, LMIC	+
For home dialysis, tasks were managing treatment, monitoring, titrating medications, adopting aseptic techniques.	ESKD	HIC, LMIC	++
Pretransplantation, specific adjustment tasks included: hospital visits, tests and organising 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 healthcare 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	++

Continued

Table 4 Continued

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

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

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 healthcare 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]

Pretransplantation 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 healthcare 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 non-governmental organisations.[48 49 125 161] In settings with coverage of RRT, socioeconomically 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 towards patients' experiential knowledge.[102 173]

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, organised raffles to collect money or obtained loans.[47–49 125] They also contacted treatment centres, other patients, hospitals and non-government organisations 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 organisations.[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 healthcare 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 healthcare professionals, downplayed their knowledge in front of them.[210] Patients and carers were responsible for obtaining and carrying their medical files and test results to appointments when the healthcare 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' socioeconomic 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 towards 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 use 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 hours telephone access for advice.[61,69] Family members were afraid to bother the healthcare team,[246] and perceiving little power in comparison to healthcare 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 underinsured 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

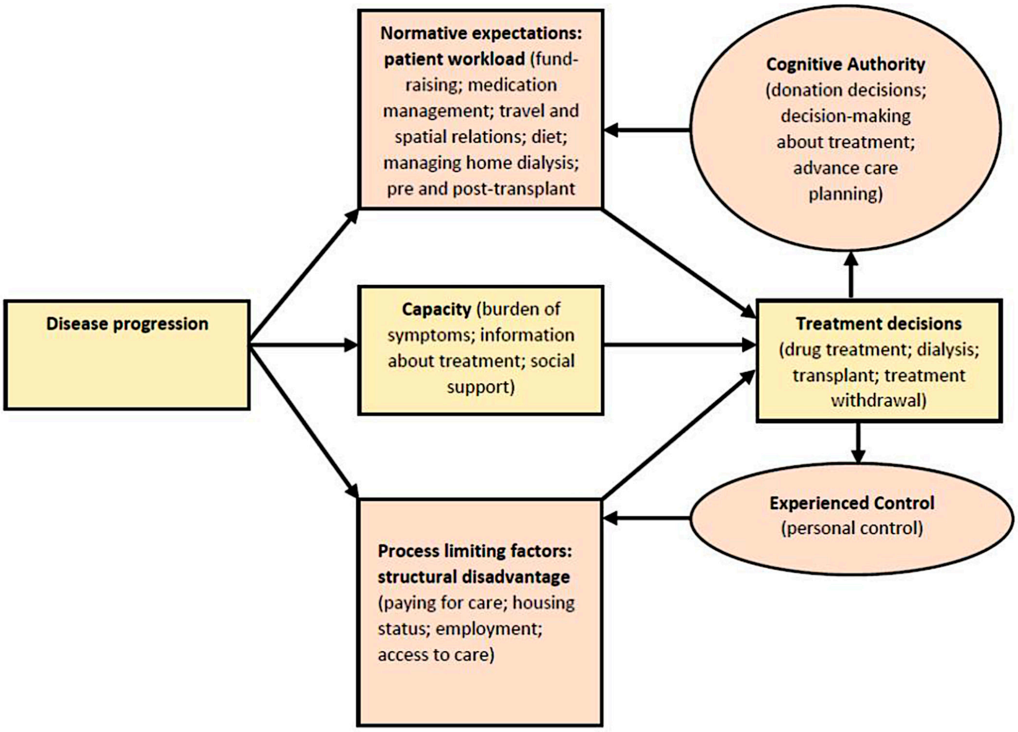

Figure 2 Thematic schema of experienced control and cognitive authority in chronic kidney disease.

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 healthcare systems; dialysis and transplantation costs often lead to financial ruin of the family, discontinuation and death.[324] In fact, patients, families and healthcare 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 2 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 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 towards 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 using 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 high-income 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 coordinated 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 patients' 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.

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