BMJ Open  Work of being an adult patient with chronic kidney disease: a systematic review of qualitative studies

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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

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.
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).\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{30, 31} PROSPERO registration number is CRD42014014547. This review follows the Enhancing Transparency in Reporting the Synthesis of Qualitative Research framework.\textsuperscript{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.\textsuperscript{33} 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.

**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.\textsuperscript{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.\textsuperscript{34} The coding frame drew on concepts from the Burden of Treatment Theory and the Cognitive Authority Theory.\textsuperscript{18–21, 29, 31, 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: 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. 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. 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. Poorly funded or unfunded healthcare resulted in fragmented treatment across healthcare systems. 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. 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. Medication was sometimes counterfeit, obtained on the black market, as legitimate medication was beyond patients’ reach. 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    | 2012 | Norway           | 5 H, East, West       | 11       |        | ESKD            | Interviews                          | Critical discourse                         |
| Aasen et al    | 2012 | Norway           | 5 H, East, West       | 7        |        | ESKD            | Interviews                          | Critical discourse                         |
| Aasen et al    | 2012 | Norway           | 5 H, East, West       | 11       | 17     | ESKD            | Interviews                          | Critical discourse                         |
| Al-Arabi       | 2012 | Norway           | H, East, West         | 11       |        | ESKD            | Interviews                          | Critical discourse                         |
| Allen et al    | 2012 | USA              | 1 C, Southwest        | 80       |        | ESKD            | Interviews                          | Naturalistic inquiry, thematic             |
| Allen et al    | 2011 | Canada           | 1 H, urban            | 7        |        | ESKD            | Interviews                          | Participation action, thematic              |
| Allen et al    | 2015 | Canada           | 2 H                   | 6        | 11     | ESKD            | Interviews                          | Thematic                                   |
| Anderson et al | 2008 | Australia        | 9 H, 17 C             | 241      |        | ESKD            | Interviews                          | Thematic                                   |
| Anderson et al | 2012 | Australia        | 9 H, 17 C             | 241      |        | ESKD            | Interviews                          | Thematic                                   |
| Arslan and Ege | 2009 | Turkey           | 1 H, Kenya            | 10       |        | ESKD            | Interviews                          | Content                                    |
| Ashby et al    | 2005 | Australia        | 2 H, Melbourne        | 16       |        | ESKD            | Interviews                          | Grounded theory                           |
| Avril-Sephula et al | 2014 | UK               | 1 H, North            | 8        |        | ESKD            | Interviews                          | Thematic                                   |
| Axelsson et al | 2012 | Sweden           | 2 H, 2 C              | 8        |        | ESKD            | Interviews                          | Phenomenological, hermeneutical            |
| Axelsson et al | 2012 | Sweden           | 2 H, 2 C              | 8        |        | ESKD            | Interviews                          | Phenomenological, hermeneutical            |
| Axelsson et al | 2015 | Sweden           | 2 H, 1 C, urban       | 14       |        | ESKD            | Interviews                          | Content                                    |
| Bailey et al   | 2015 | UK               | Bristol               | 32       |        | Transplanted    | Interviews                          | Constant comparison                       |
| Bailey et al   | 2016 | UK               | Bristol               | 13       |        | Transplanted    | Interviews                          | Constant comparison                       |
| Baille and Lankshear | 2015 | UK               | Wales                 | 16       | 9      | ESKD            | Interviews                          | Thematic                                   |
| Baille and Lankshear | 2015 | UK               | Wales                 | 16       | 9      | ESKD            | Interviews                          | Thematic                                   |
| Barbosa and Valadas | 2009 | Brazil           | 1 C, Rio de Janeiro   | 10       |        | ESKD            | Interviews                          | Grounded theory                           |
| Bath et al     | 2003 | UK               | South                 | 10       |        | ESKD            | Interviews                          | Phenomenological                          |
| Beanlands et al| 2005 | Canada           | Ontario               | 37       |        | ESKD            | Interviews                          | Grounded theory                           |
| Bennett et al  | 2013 | Australia        | 4 C                   | 9        | 2      | ESKD            | Interviews facilitated by images    | Thematic                                   |
| Blogg and Hyde | 2008 | Australia        | Urban                 | 5        |        | ESKD            | Interviews                          | Ethnographic                              |
| Boaz and Morgan| 2014 | UK               | Rural, urban          | 25       |        | Transplanted    | Interviews                          | Constant comparison                       |
| Bourbonnais and Tousignant | 2012 | Canada          | 1 H                   | 25       |        | ESKD            | Interviews                          | Content                                    |

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

Continued
| Author               | Year | Country         | Setting                  | Patients | Carers | Type of patient | Data collection | Data analysis reported                |
|----------------------|------|-----------------|--------------------------|----------|--------|-----------------|-----------------|----------------------------------------|
| Curtin et al         | 2002 | USA             | 18                       | ESKD     |        | Interviews      | Content         |                                        |
| da Silva et al       | 2016 | Brazil          | 1 C, Northeast           | 30       |        | ESKD            | Interviews      | Content and thematic                   |
| da Silva et al       | 2011 | Brazil          | 1 H, Rio Grande do Sul  | 9        |        | ESKD            | Interviews      | Qualitative                            |
| Darrell et al        | 2016 | USA             | 1 H                      | 12       |        | ESKD            | Interviews      | Giorgi's method                        |
| Davison et al        | 2006 | Canada          | Alberta                  | 24       |        | ESKD            | Interviews      | Constant comparison, iterative         |
| Davison et al        | 2006 | Canada          | 1 H                      | 19       |        | ESKD            | Interviews      | Inductive                              |
| Brito et al          | 2015 | Brazil          | 1 H, Minas Gerais        | 50       |        | Transplanted    | Interviews      | Collective subject technique           |
| Rosenroll et al      | 2013 | Canada          | 1 H                      | 10       |        | ESKD            | Interviews      | Constant comparison                    |
| Dekkers et al        | 2005 | The Netherlands | 2 C                      | 7        |        | ESKD            | Interviews      | Phenomenological                       |
| DePasquale et al     | 2013 | USA             | NP, 1 C                  | 68       | 62     | CKD            | Group interviews| Mixed method                           |
| dos Reis et al       | 2008 | Brazil          | 1 H, Sao Paulo           | 8        |        | ESKD            | Interviews      | Content                               |
| dos Santos et al     | 2011 | Brazil          | Rio de Janeiro           | 8        |        | ESKD            | Interviews      | Grounded theory                        |
| dos Santos et al     | 2015 | Brazil          | 3 NP, Rio Grande do Sul | 20       |        | Transplanted    | Interviews      | Critical incident                      |
| Ekelund et al        | 2010 | Sweden          | 1 C, South               | 39       | 21     | ESKD            | Interviews      | Content                               |
| Erlang et al         | 2015 | Denmark         | 1 H                      | 9        |        | CKD (predialysis)| Interviews      | Systematic text condensation           |
| Eslami et al         | 2016 | Iran            | 4 C, Isfahan             | 20       |        | ESKD            | Interviews      | Thematic                              |
| Finnegan-John et al  | 2013 | UK              | 1 trust, London          | 118      | 12     | CKD/ESKD       | Interviews      | Thematic                              |
| Flores et al         | 2004 | Brazil          | 1 H, Rio Grande do Sul  | 9        |        | ESKD            | Interviews      | Content                               |
| Fraguas et al        | 2008 | Brazil          | 2 H, Minas Gerais        | 18       |        | ESKD            | Interviews      | Content                               |
| Ghadami et al        | 2012 | Iran            | 1 charity, Isfahan       | 15       |        | Transplanted    | Interviews      | Content                               |
| Giles et al          | 2003 | Canada          | 1 H, urban               | 4        |        | ESKD            | Interviews      | Thematic                              |
| Giles et al          | 2005 | Canada          | New Mexico               | 4        |        | ESKD            | Interviews      | Phenomenological                       |
| Goff et al           | 2015 | USA             | New Mexico               | 13       | 9      | ESKD            | Interviews      | Thematic                              |
| Goldane et al        | 2011 | USA             | 1 C                      | 39       |        | Transplanted    | Focus groups and| Iterative analysis                     |
| Gordon et al         | 2007 | USA             | Transplanted             | 20       |        | Diary entries   | Thematic       |                                        |
| Gordon et al         | 2009 | USA             | Transplanted             | 82       |        | Transplanted    | Interviews      | Thematic                              |
| Gricio et al         | 2009 | Brazil          | 1 H, Sao Paulo           | 20       |        | ESKD            | Interviews      | Thematic                              |
| Author         | Year | Country     | Setting          | Patients | Carers | Type of patient | Data collection | Data analysis reported               |
|---------------|------|-------------|------------------|----------|--------|----------------|----------------|--------------------------------------|
| Gullick et al | 2016 | Australia   | 1H, Sydney       | 11       | 5      | ESKD           | Interviews      | Hermeneutic interpretation           |
| Hagren et al  | 2001 | Sweden      | 1H               |          |        | ESKD           | Interviews      | Content                              |
| Hagren et al  | 2005 | Sweden      | 3H               | 41       |        | ESKD           | Interviews      | Content                              |
| Hain et al    | 2011 | USA         | 6 C, Southeast   | 56       |        | ESKD           | Interviews      | Story inquiry method                 |
| Hanson et al  | 2016 | Australia   | 1 C, West        | 20       |        | ESKD           | Interviews      | Thematic                            |
| Harrington et al | 2016 | UK                  | 8H               | 24       |        | Transplanted   | Interviews      | Thematic                            |
| Harwood et al | 2014 | Canada      | 1H               | 13       |        | ESKD           | Interviews      | Content                              |
| Harwood et al | 2005 | UK          | 1H, London       | 11       |        | CKD/ESKD       | Interviews      | Content                              |
| Haspeslagh et al | 2013 | Belgium    | 1H, Leuven       | 31       |        | Transplanted   | Interviews and questionnaires          | Thematic                            |
| Heiwe et al   | 2003 | Sweden      | 1H, Karolinska   | 16       |        | ESKD           | Interviews      | Contextual                          |
| Heiwe et al   | 2004 | Sweden      | 1H, Karolinska   | 16       |        | CKD/ESKD       | Interviews      | Contextual                          |
| Herbias et al | 2016 | Chile       | 1C, Santiago     | 12       |        | ESKD           | Interviews      | Streubert's method                  |
| Herlin et al  | 2010 | Sweden      | 3C               | 9        |        | ESKD           | Interviews      | Giorgi's method                     |
| Hollingdale et al | 2008 | UK               |                  | 20       |        | CKD/ESKD       | Focus groups    | Framework approach                  |
| Hong et al    | 2017 | Singapore   | 1H               | 14       |        | ESKD           | Interviews      | Thematic                            |
| Horigan et al | 2013 | USA         | 1C, Mid-Atlantic | 14       |        | ESKD           | Interviews      | Content                              |
| Hutchison et al | 2017 | Canada     | 1 clinic, urban  | 9        | 16     | CKD/ESKD       | Interviews      | Interpretive description            |
| Iles-Smith et al | 2005 | UK          | 1 C, Manchester  | 10       |        | CKD (predialysis) | Interviews       | Thematic                            |
| Johnston et al | 2012 | UK          | 1 trust, London  | 9        |        | ESKD           | Interviews      | Thematic                            |
| Kaba et al    | 2007 | Greece      | 2H, Athens       | 23       |        | ESKD           | Interviews      | Qualitative                          |
| Kahn et al    | 2015 | USA         | 2 NP, New York   | 34       |        | CKD            | Interviews      | Thematic                            |
| Karamanidou et al | 2014 | UK          | 1 C, London      | 7        |        | ESKD           | Interviews      | Interpretative, phenomenological     |
| Kazley et al  | 2015 | USA         | 1 C, Southeast   | 20       |        | CKD/ESKD       | Focus groups    | Thematic                            |
| Keeping et al | 2001 | Canada      | East             | 8        |        | ESKD           | Interviews      | Thematic                            |
| Kierans et al | 2001 | Ireland     |                  | 5        |        | ESKD           | Interviews, life stories             | Phenomenological                     |
| Kierans et al | 2005 | Ireland     |                  | 5        |        | CKD/ESKD       | Interviews      | Phenomenological                     |
| Kierans et al | 2013 | Mexico      | 1H, Jalisco      | 51       | 87     | ESKD, transplanted | Interviews, observation*          | Ethnographic approach               |
| King et al    | 2002 | UK          | 1 C              | 22       |        | CKD/ESKD       | Interviews      | Template approach                   |
| Knih et al    | 2013 | Brazil      | 1 C, South       | 20       |        | ESKD           | Interviews      | Content                              |
| Krespi-Boothby et al | 2004 | UK          | 1 H, 4 C        | 16       |        | ESKD           | Interviews      | Thematic                            |
| Author                  | Year | Country       | Setting            | Patients | Carers | Type of patient | Data collection | Data analysis reported       |
|-------------------------|------|---------------|--------------------|----------|--------|-----------------|----------------|-------------------------------|
| Krespi-Boothby et al    | 2013 | UK            | 1 H, 4 C           | 16       |        | ESKD            | Interviews      | Template approach            |
| Ladin et al             | 2016 | USA           | 2 C, Massachusetts | 23       |        | ESKD            | Interviews      | Thematic                     |
| Ladin et al             | 2017 | USA           | 2 C, Massachusetts | 31       |        | ESKD            | Interviews      | Thematic Nutbeam's framework |
| Landreneau et al         | 2006 | USA           | 1 C, 1 NP, South   | 6        |        | ESKD            | Interviews      | Colaiazzi's method           |
| Landreneau et al         | 2007 | USA           | 2 C, South         | 12       |        | ESKD            | Interviews      | Colaiazzi's method           |
| Lawrence et al           | 2013 | UK            | 1 C                | 10       |        | ESKD            | Interviews      | Conceptual and categorical   |
| Lederer et al            | 2015 | USA           | 1 C                | 32       |        | ESKD            | Interviews      | Thematic                     |
| Lee et al                | 2008 | Denmark       | Diverse            | 27       | 18     | ESKD            | Focus groups    | Thematic                     |
| Lee et al                | 2016 | Singapore     | 1 organisation     | 20       |        | ESKD            | Interviews      | Thematic                     |
| Lenci et al              | 2012 | USA           |                    | 4        |        | ESKD            | Interviews      | Thematic                     |
| Leung et al              | 2007 | Hong Kong     | 1 C                | 12       |        | ESKD            | Interviews      | Content                      |
| Lewis et al              | 2015 | UK            | 14 H               | 40       |        | ESKD            | Interviews      | Grounded theory             |
| Lin et al                | 2015 | Taiwan        | 1 C, S, rural      | 15       |        | ESKD            | Interviews      | Constant comparison         |
| Lindberg et al           | 2008 | Sweden        | 1 C, mid-country   | 10       |        | ESKD            | Interviews      | Content                      |
| Lindberg et al           | 2013 | Sweden        | 1 C, mid-country   | 10       |        | ESKD            | Interviews      | Content                      |
| Lindsay et al            | 2014 | Australia     | 1 C, Sydney        | 7        |        | ESKD            | Interviews      | Thematic                     |
| Llewellyn et al          | 2014 | UK            | 4 C, London        | 19       |        | ESKD            | Interviews      | Thematic                     |
| Lo et al                 | 2016 | Australia     | 4 H, Melbourne,    | 58       |        | CKD/ESKD        | Interviews and  | Thematic                     |
| Lopes et al              | 2014 | Brazil        | 1 C, Santa Catarina| 12       |        | ESKD            | Interviews      | Interpretative              |
| Lopez-Vargas et al       | 2014 | Australia     | 3 C, New South     | 38       |        | CKD            | Focus groups    | Thematic                     |
| Lopez-Vargas et al       | 2016 | Australia     | 3 C, New South     | 38       |        | CKD/ESKD        | Focus groups    | Thematic                     |
| Lovink et al             | 2015 | The Netherlands| 1 C                | 12       |        | ESKD            | Interviews      | Content                      |
| Low et al                | 2014 | UK            | 5 C, Southeast     | 26       |        | ESKD            | Interviews      | Thematic                     |
| Machado et al            | 2003 | Brazil        | Sao Paulo          | 18       |        | ESKD            | Interviews      | Discourse                    |
| Marques et al            | 2014 | Brazil        | Paraná             | 10       |        | ESKD            | Interviews      | Content                      |
| Martin-McDonald et al    | 2003 | Australia     | 5 C                | 10       |        | ESKD            | Interviews      | Thematic                     |
| Martin-McDonald et al    | 2003 | Australia     | 1 C                | 10       |        | ESKD            | Interviews      | Thematic                     |
| Mason et al              | 2007 | UK            | 1 C                | 9        | 5      | CKD            | Focus groups    | Framework approach          |
| McCarthy et al           | 2010 | Australia     | 1 H                | 5        |        | ESKD            | Interviews      | Sequential                   |

Continued
| Author             | Year | Country | Setting                           | Patients | Carers | Type of patient | Data collection | Data analysis reported   |
|--------------------|------|---------|-----------------------------------|----------|--------|-----------------|----------------|--------------------------|
| McKillop et al     | 2013 | UK      | Clinics                           | 10       |        | CKD             | Interviews       | Thematic                |
| Mercado-Martinez et al | 2014 | Mexico  | Jalisco, San Luis Potosi          | 21       |        | Transplanted    | Interviews       | Thematic                |
| Mercado-Martinez et al | 2015 | Brazil  | 1H, South                         | 11       | 5      | ESKD            | Interviews       | Content                 |
| Mercado-Martinez et al | 2015 | Mexico  | Public H and institutions, Jalisco | 37       | 50     | ESKD            | Interviews       | Content                 |
| Mitchell et al     | 2009 | UK      | 1 C                               | 10       |        | CKD/ESKD        | Interviews       | Content                 |
| Molzahn et al      | 2012 | Canada  | Middle size city                  | 14       |        | CKD             | Interviews       | Thematic                |
| Moran et al        | 2009 | Ireland | 1H                                | 16       |        | ESKD            | Interviews       | Interpretive            |
| Moran et al        | 2009 | Ireland | 1H                                | 16       |        | ESKD            | Interviews       | Interpretive            |
| Moran et al        | 2011 | Ireland | H                                 | 16       |        | ESKD            | Interviews       | Interpretative          |
| Morton et al       | 2010 | Australia | Diverse                         | 95       |        | ESKD            | Interviews       | Thematic                |
| Muduma et al       | 2016 | UK      | 2 C                               | 37       |        | Transplanted    | Focus groups     | Qualitative             |
| Nagpal et al       | 2017 | USA     | 1 C, New York                     | 36       |        | ESKD            | Interviews       | Coding                  |
| Namiki et al       | 2010 | Australia | 1 H                             | 4        |        | ESKD            | Interviews       | Thematic                |
| Ni et al           | 2017 | China   | 1 C, Jiangsu                      | 23       |        | ESKD            | Interviews       | Continuous comparison  |
| Nobahar et al      | 2016 | Iran    | 1H, Semnan                        | 8        | 12     | ESKD            | Interviews       | Granheim and Lundman’s approach |
| Nobahar et al      | 2016 | Iran    | 1H, Semnan                        | 8        | 12     | ESKD            | Interviews       | Granheim and Lundman’s approach |
| Noble et al        | 2009 | UK      | 1 service, London                 | 30       | 17     | ESKD            | Interviews       | Constant comparison    |
| Noble et al        | 2010 | UK      | 1 service, London                 | 30       | 17     | ESKD            | Interviews       | Constant comparison    |
| Noble et al        | 2012 | UK      | 1 service                         | 19       |        | ESKD            | Interviews       | Constant comparison    |
| Nygardh et al      | 2011 | Sweden  | 1 C, South                        | 12       |        | CKD (predialysis) | Interviews       | Content                 |
| Nygardh et al      | 2011 | Sweden  | 1 C, South                        | 20       |        | CKD             | Interviews       | Latent content          |
| Malheiro Oliveira et al | 2012 | Brazil  | Bahia                             | 19       |        | ESKD            | Interviews       | Categorical             |
| Orr et al          | 2007 | UK      | 1 C                              | 26       |        | Transplanted    | Focus groups     | Thematic                |
| Orr et al          | 2007 | UK      | 1 C                              | 26       |        | Transplanted    | Focus groups     | Thematic                |
| Oyegbile et al     | 2016 | Nigeria | 2H, Southwest                     | 15       |        | ESKD            | Interviews       | Content                 |
| Pelletier-Hibbert et al | 2001 | Canada  | East                             | 41       |        | ESKD            | Focus groups     | Thematic                |
| Piccoli et al      | 2010 | Italy   | 1H                                | 12       |        | CKD/ESKD, transplanted | Focus groups | Not clear               |
| Pietrovs et al     | 2006 | Brazil  | 1H, Paraná                        | 15       |        | ESKD            | Interviews       | Content                 |
| Pilger et al       | 2010 | Brazil  | 1 C, Paraná                       | 22       |        | ESKD            | Interviews       | Thematic                |
| Author          | Year | Country         | Setting                          | Patients | Carers | Type of patient | Data collection | Data analysis reported         |
|-----------------|------|-----------------|----------------------------------|----------|--------|-----------------|----------------|-----------------------------|
| Polaschek et al | 2003 | New Zealand     | 1 C                              | 6        |        | ESKD            | Interviews      | Thematic                   |
| Polaschek et al | 2006 | New Zealand     | 1 regional department            | 20       |        | ESKD            | Interviews      | Thematic                   |
| Polaschek et al | 2007 | New Zealand     | 1 regional department            | 20       |        | ESKD            | Interviews      | Thematic                   |
| Prieto et al    | 2011 | Spain           | Andalusia                        | 22       |        | ESKD            | Interviews      | Discourse                  |
| Rabiei et al    | 2015 | Iran            | Isfahan                          | 20       |        | ESKD            | Interviews      | Thematic                   |
| Ravenscroft et al | 2005 | Canada          | 3 C                              | 7        |        | ESKD            | Interviews      | Inductive                  |
| Reid et al      | 2012 | UK              | 1 C, clinics                      | 11       |        | CKD/ESKD        | Interviews      | Thematic                   |
| Reta et al      | 2014 | Spain           | 1 H, Araba                       | 14       |        | ESKD            | Interviews      | Content                    |
| Richard et al   | 2010 | USA             | 14                               | ESKD     |        | Interviews      | Cultural negotiation model framework |
| Rifkin et al    | 2010 | USA             | 1 C                              | 20       |        | CKD/ESKD        | Interviews      | Thematic                   |
| Rix et al       | 2014 | Australia       | New South Wales, rural           | 18       |        | ESKD            | Interviews      | Thematic                   |
| Rix et al       | 2015 | Australia       | New South Wales, rural           | 18       | 29     | ESKD            | Interviews      | Thematic                   |
| Rodrigues et al | 2011 | Brazil          | 1 C, South                       | 8        |        | ESKD            | Interviews      | Categorical                |
| Ros et al       | 2012 | USA             | 1 H, Maryland                    | 19       |        | ESKD            | Focus groups    | Thematic                   |
| Roso et al      | 2013 | Brazil          | 1 H, South                       | 15       |        | ESKD            | Narrative interviews | Thematic         |
| Russ et al      | 2005 | USA             | 2 C, California                  | 43       |        | ESKD            | Interviews      | Anthropoligic study       |
| Russell et al   | 2003 | USA             | 1 C, Midwest                     | 16       |        | Transplanted    | Interviews      | Constant comparison       |
| Rygh et al      | 2012 | Norway          | North                           | 11       |        | ESKD            | Interviews      | Inductive, actor's point of view |
| Sadala et al    | 2012 | Brazil          | 1 H                             | 19       |        | ESKD            | Narrative interviews | Phenomenological, hermeunteal |
| Sahaf et al     | 2017 | Iran            | 2 hour, Sari                    | 9        |        | ESKD            | Interviews      | van Manen's thematic       |
| Salvalaggio et al | 2003 | Canada         | 1 H, Ontario                     | 12       |        | ESKD            | Interviews      | Immersion/crystalisation  |
| Schell et al    | 2012 | USA             | 1 university system, NP, North Carolina | 29       | 11     | CKD/ESKD        | Interviews and focus groups | Thematic               |
| Schipper et al  | 2014 | The Netherlands | 5 H                              | 30       |        | Transplanted    | Focus groups and interviews | Thematic               |
| Schmid-Mohler et al | 2014 | Switzerland     | 1 H, Zurich                     | 12       |        | Transplanted    | Interviews      | Content                    |
| Schober et al   | 2016 | USA             | 14 states                       | 48       |        | ESKD            | Interviews      | Thematic                   |
| Seah et al      | 2013 | Singapore       | 3 H                             | 9        |        | ESKD            | Interviews      | Interpretative phenomenological |
| Author                     | Year | Country     | Setting            | Patients | Carers | Type of patient | Data collection | Data analysis reported                      |
|---------------------------|------|-------------|--------------------|----------|--------|-----------------|----------------|--------------------------------------------|
| Shahgholian et al          | 2015 | Iran        | 1H, Isfahan        | 17       |        | ESKD            | Interviews      | Colaizzi's method                           |
| Shaw et al                 | 2015 | New Zealand | Diverse           | 24       |        | ESKD            | Interviews      | Phenomenological                            |
| Sheu et al                 | 2012 | USA         | Maryland           | 27       | 23     | ESKD            | Focus groups    | Thematic                                   |
| Shih et al                 | 2011 | New Zealand | 1C, North          | 7        |        | ESKD            | Interviews      | Hermeneutical and thematic                 |
| Shirazian et al            | 2016 | USA         | 1C, Northeast      | 23       |        | CKD             | Focus groups    | Thematic                                   |
| Sieverdes et al            | 2015 | USA         | 1C, South Carolina | 27       |        | Transplanted    | Focus groups    | Thematic                                   |
| Smith et al                | 2010 | USA         | 2C                 | 19       |        | ESKD            | Focus groups    | Thematic                                   |
| Spiers et al               | 2015 | UK          | 1C, London         | 4        |        | Transplanted    | Interviews      | Interpretative phenomenological             |
| Spiers et al               | 2016 | UK          | 2 online groups    | 10       |        | ESKD            | Interviews      | Thematic                                   |
| Stanfill et al             | 2012 | USA         | 1C, mid-South      | 7        |        | Transplanted    | Focus groups    | Iterative                                  |
| Stewart et al              | 2012 | USA         | 2C, urban          | 19       |        | ESKD            | Interviews      | Coding                                     |
| Tanyi et al                | 2006 | USA         | Mid-West           | 16       |        | ESKD            | Interviews      | Colaizzi's method                           |
| Tanyi et al                | 2008 | USA         | 2C, mid-West       | 16       |        | ESKD            | Interviews      | Colaizzi's method                           |
| Tanyi et al                | 2008 | USA         | Mid-West           | 16       |        | ESKD            | Interviews      | Colaizzi's method                           |
| Tavares et al              | 2016 | Brazil      | 1H, Rio de Janeiro | 19       |        | ESKD            | Interviews and groups | Content |
| Taylor et al               | 2016 | Australia   | 2H, Sydney         | 26       |        | ESKD            | Interviews      | Thematic                                   |
| Taylor et al               | 2015 | UK          | 6 trusts           | 15       | 11     | ESKD            | Interviews      | Constant comparison                         |
| Theofilou et al            | 2013 | Greece      | 1H, Athens         | 10       |        | ESKD            | Interviews      | Phenomenological                            |
| Thomé et al                | 2011 | Brazil      | 1H, Rio Grande do Sul | 10     |        | ESKD            | Interviews      | Cultural                                   |
| Tielen et al               | 2011 | The Netherlands | 1C        | 26       |        | Transplanted    | Interviews      | Q methodology                              |
| Tijerina et al             | 2006 | USA         | 8C, Texas          | 26       |        | ESKD            | Interviews      | Coding                                     |
| Tong et al                 | 2009 | Australia   | 4H, Brisbane, Sydney, Melbourne | 63       |        | CKD/ESKD        | Focus groups    | Thematic                                   |
| Tong et al                 | 2013 | Italy       | 4C, Bari, Marsala, Nissoria, Taranto | 22       | 20     | ESKD            | Interviews      | Thematic                                   |
| Tong et al                 | 2015 | Australia   | 1C, Adelaide       | 15       |        | CKD/ESKD        | Interviews      | Thematic                                   |
| Tonkin-Crine et al         | 2015 | UK          | 9C                 | 42       |        | ESKD            | Interviews      | Thematic                                   |
| Torchi et al               | 2014 | Brazil      | 1C, Rio de Janeiro | 10       |        | ESKD            | Interviews      | Collective subject technique               |
| Tovazzi et al              | 2012 | Italy       | North              | 12       |        | ESKD            | Interviews      | Phenomenological                           |
| Tweed et al                | 2005 | UK          | 1C, Leicester      | 9        |        | ESKD            | Interviews      | Phenomenological                           |

Continued
Table 2  Continued

| Author          | Year | Country               | Setting                      | Patients | Carers | Type of patient | Data collection | Data analysis reported |
|-----------------|------|-----------------------|------------------------------|----------|--------|-----------------|-------------------|------------------------|
| Urstad et al    | 2012 | Norway                | 1 C                          | 15       |        | Transplanted    | Interviews        | Hermeneutic            |
| Valsaraj et al  | 2014 | India                 | 1 H, South Karnatake         | 10       |        | ESKD            | Interviews        | Phenomenological       |
| Velez et al     | 2006 | Spain                 | 1 C                          | 12       |        | ESKD            | Interviews        | Thematic               |
| Vestman et al   | 2014 | Sweden                | 1 H                          | 9        |        | ESKD            | Written narratives| Thematic               |
| Visser et al    | 2009 | The Netherlands       | 1 C                          | 14       |        | ESKD            | Interviews        | Thematic               |
| Wachterman et al| 2015 | USA                   | 1 C                          | 16       |        | ESKD            | Interviews        | Thematic               |
| Walker et al    | 2012 | UK                    | 1 H                          | 9        |        | CKD             | Interviews        | Thematic               |
| Walker et al    | 2016 | New Zealand           | 3 C                          | 43       | 9      | ESKD            | Interviews        | Thematic               |
| Walker et al    | 2016 | New Zealand           | 3 C                          | 43       | 9      | ESKD            | Interviews        | Thematic               |
| Walker et al    | 2017 | New Zealand           | 3 C                          | 13       |        | ESKD            | Interviews        | Thematic               |
| Walton et al    | 2002 | USA                   | 1 H, rural, Northwest        | 11       |        | ESKD            | Interviews        | Grounded theory        |
| Walton          | 2007 | USA                   | 1 C                          | 21       |        | ESKD            | Interviews        | Grounded theory        |
| Wei             | 2000 | USA                   | 2 C, rural, Northwest        | 14       |        | ESKD            | Interviews        | Thematic               |
| Wells           | 2015 | USA                   | 3 C, 1 NP, Texas             | 17       | 17     | ESKD            | Interviews        | Thematic               |
| Wells           | 2015 | USA                   | 3 C, 1 NP, Texas             | 15       | 21     | ESKD            | Interviews        | Thematic               |
| White et al     | 2004 | USA                   | 1 C, Colorado                | 6        | 9      | ESKD            | Interviews        | Thematic               |
| Wiederhold et al| 2012 | Germany               | 1 C                          | 10       |        | Transplanted    | Interviews        | Content                |
| Wilkinson et al | 2011 | UK                    | Luton, West London, Leicester| 48       |        | ESKD            | Interviews        | Thematic               |
| Wilkinson et al | 2014 | UK                    | 4 C                          | 16       | 45     | Transplanted    | Interviews and focus groups | Thematic               |
| Wilkinson et al | 2016 | UK                    | 4 C                          | 16       | 45     | Transplanted    | Interviews and focus groups | Thematic               |
| Williams et al  | 2009 | Australia             | 2 H                          | 20       |        | CKD             | Interviews        | Qualitative           |
| Williams et al  | 2008 | Australia             | 2 H, Melbourne               | 23       |        | CKD             | Interviews and focus groups | Interpretative         |
| Williams et al  | 2015 | UK                    | 3 C                          | 15       | 15     | ESKD            | Focus groups      | Thematic               |
| Wilson et al    | 2012 | UK                    | 1 C, Northern England        | 20       |        | CKD             | Interviews        | Thematic               |
| Wu et al        | 2015 | Taiwan                | 2 C, Central                 | 15       |        | ESKD            | Interviews        | Thematic               |

Continued
Table 2  Continued

| Author                     | Year | Country       | Setting      | Patients | Carers | Type of patient | Data collection | Data analysis reported      |
|---------------------------|------|---------------|--------------|----------|--------|----------------|-----------------|----------------------------|
| Xi et al                  | 2011 | Canada, Ontario | 1 C, Ontario | 13       | ESKD   | Interviews     | Thematic        |                            |
| Xi et al                  | 2013 | Canada, Ontario | 1 C, Ontario | 10       | ESKD   | Interviews     | Thematic        |                            |
| Yeun et al                | 2016 | South Korea   | 1 H, Seoul   | 33       | ESKD   | Interviews     | Q methodology   |                            |
| Yngman-Uhlin et al        | 2010 | Sweden        | Southeast    | 14       | ESKD   | Interviews     | Phenomenological |                            |
| Yngman-Uhlin et al        | 2016 | Sweden, Southeast | 1 H, Southeast | 8       | ESKD   | Interviews     | Content          |                            |
| Yodchais et al            | 2016 | Thailand      | 2 H, Songkla | 20       | ESKD   | Interviews     | Qualitative      |                            |
| Yodchais et al            | 2012 | Thailand      | 1 C, South   | 5        | ESKD   | Interviews     | Grounded theory  |                            |
| Yu et al                  | 2014 | Singapore     | NKF          | 32       | ESKD   | Interviews     | Thematic        |                            |
| Yumang et al              | 2009 | Canada, Quebec | 1 H, Quebec  | 9        | ESKD   | Interviews     | Colaizzi's method |                            |
| Ziegert et al             | 2001 | Sweden        |              | 12       | ESKD   | Interviews     | Pragmatic approach |                            |
| Ziegert et al             | 2009 | Sweden, Southwest |          | 13       | ESKD   | Interviews     | Content          |                            |
| Ziegert et al             | 2006 | 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.

Illustrative quotations

**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’s going to give a kidney to somebody else. She was willing to—she was willing to do something for you, for the sake of you, for the sake of you (UK patient). It was a kind of a twist. You don’t have to do anything. It’s not what you do. It’s like—

**Workload**

Sometimes I have to sit and wait at least an hour and have to call and say my ride is not here yet, which makes me there, a nurse and a patient. And then when they get off the machine and they—coming to pick you up, and you'll have to sit and wait for a long time. And I don't want to sit and wait. And there's always the worry of the transplant. Sometimes I need to sit and wait at least an hour and I have to call and say my ride is not here yet, which makes me there, a nurse and a patient. And then when they get off the machine and they—coming to pick you up, and you'll have to sit and wait for a long time. And I don't want to sit and wait. And there's always the worry of the transplant.
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. 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.

**Housing conditions**

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

**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. 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.

**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. Patients who obtained information about the high costs of immunosuppressants and realised that they could not afford them, were forced to continue with dialysis until it failed. 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.

**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. What’s that I like (talking on home dialysis, patient from Canada). 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).

**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).

**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). 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). 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).

**Risk, whatever their treatment modality, as in the case of many undocumented and uninsured immigrants in the USA. 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 hospitals, long delays to undergo examinations, limited structure, patients reported shortage of public specialised as translators at appointments. Where language was care professionals; family members and neighbours acted as translators at appointments.

**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.** 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.

**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. Women also faced potential family conflicts if they followed prescribed diets. 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.

**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
| Primary category | Secondary category | Summary results |
|------------------|--------------------|-----------------|
| Structural       | Access to care     | Socioeconomic status is central to experience of CKD.35 37–62 125 |
|                  |                    | Treatment costs were major obstacle to care as limited access to healthcare for the uninsured or underinsured.35 40 48 50 62 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.35 47–49 52 66 67 68 125 |
| 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| Self-care          | 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 |
|                  |                    | 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 52 |
|                  |                    | 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.52 173 |
| 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 52 125 171 216 218 |
| 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.53 134–145 |
|                  |                    | 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
### 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 85 175–178 181–186 |
| **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. | 35 89 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. | 51 102 223 231–234  
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. | 38 44 60 247 259  
Patients ought to maintain a sense of normalcy, integrating dialysis community into their network. | 42 139 210 240  
Younger patients sometimes considered home dialysis as an opportunity for employment and contact with social networks. | 61 152 |
| **Experienced control** | When clinicians failed to discuss care, eligibility for transplant and potential donors, patients felt disempowered. | 39 57 58 61 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  
Carers’ involvement was a frequent concern for patients. | 42 139 210 240 |
| **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
patients because of pick-up delays, long distances or high costs.\textsuperscript{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.\textsuperscript{55} 134–145 The treatment was seen by most patients as an emotional and time imposition that caused boredom and frustration.\textsuperscript{65} 148–152 Time was often spent waiting for visits, prescriptions and tests.\textsuperscript{55} 134–143 157 Parents also arranged child care while they were in sessions, or had to travel for treatment.\textsuperscript{49} 53 55 154 155

Home dialysis

For patients receiving home dialysis, training was required which necessitated extended periods of leave from work.\textsuperscript{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.\textsuperscript{132} 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.\textsuperscript{156} 157 163 In the case of developing peritonitis, workload increased as antibiotics had to be reconstituted and injected.\textsuperscript{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.\textsuperscript{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.\textsuperscript{132} 153 154 165 170–173 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.\textsuperscript{49} 53 164 171

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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{101} 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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{47–49} 125 They also contacted treatment centres, other patients, hospitals and non-governmental 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.\textsuperscript{47} In more

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.
affluent settings, patients also struggled to negotiate coverage of extra expenses, such as those related to home dialysis or conservative management.47 161

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 65 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 60 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.61 102 225 251–254 Other patients could sometimes supply information about dialysis options, travelling, hygiene regimens, dietary restrictions, benefit advice, timing of treatment and pain management.117 174 255–258 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.117 174 255–258 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.62 139 210 260

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.218 269 261 The experience of feelings of personal control led to increased self-confidence and well-being.45 139 251 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.61 102 107 266 267 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.13 43 61 63 197 239 240 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. 134 141 161 For many patients, home dialysis restored a sense of control and freedom to manage their schedule, especially if it was nocturnal. 31 70 138 220 263 275 Dependence on emergency care or on fund-raising tasks to cover life-saving treatment represented a severe case of lack of experienced control. 35 47–52 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. 34 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. 35 70 111 136–158 223 279 289 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. 236 286 287 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. 126 293 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. 202 235 292 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
When health systems fail to meet patients’ treatment needs, patients mobilise resources and develop coping strategies such as accepting charity or selling assets. 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. In fact, patients, families and healthcare professionals are burdened with having to choose between life and death. 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. Among other factors, advanced age, white ethnicity and chronic disease are associated with dialysis withdrawal.

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. 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. 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. 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. 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. For example, patients’ concerns and expectations about waiting lists, eligibility and allocation for transplantation could be addressed via additional information,
clinical conversations and access to specialised psychological therapists.\textsuperscript{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.\textsuperscript{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.\textsuperscript{322} For migrants with access to care, culturally competent navigator programmes could contribute to the improvement of healthcare disparities.\textsuperscript{332}

Surprisingly, patients who undergo haemodialysis tend to perceive that staff underestimate their capacities.\textsuperscript{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.\textsuperscript{28, 333}

Changes in treatment may be needed as CKD progresses to its later stages—symptom control may become the main treatment focus.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{24} Management should be coordinated among professionals, particularly for patients with ESKD and multiple morbidities,\textsuperscript{23} who frequently experience fragmented care with a substantial time and travel burden, as well as contradictory healthcare advice.\textsuperscript{25}

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.\textsuperscript{30, 335} When overwhelmed, patients may be forced to renegotiate their responsibilities with actors in the health system and their own social networks.\textsuperscript{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 practices 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, multi-pronged approach is needed to address the overwhelming BoT of CKD that, in many populations, results in premature death.\textsuperscript{8, 314} 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.\textsuperscript{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 understanding of their burden, with the objective of improving quality of care and the illness experience.
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