

Measures of treatment burden in dialysis: A scoping review

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Abstract

Background: Dialysis is a life-sustaining treatment for patients with advanced kidney failure, but it is extremely burdensome. Despite this, there are very few tools available to assess treatment burden within the dialysis population.

Objective: To conduct a scoping review of generic and disease-specific measures of treatment burden in chronic kidney disease, and assess their suitability for use within the dialysis population.

Design: We searched CINAHL, MEDLINE and the Cochrane Library for kidney disease-specific measures of treatment burden. Studies were initially included if they described the development, validation or use of a treatment burden measure or associated concept (e.g., measures of treatment satisfaction, quality of life, illness intrusiveness, disease burden etc.) in adult patients with chronic kidney disease. We also updated a previous scoping review exploring measures of treatment burden in chronic disease to identify generic treatment burden measures.

Results: One-hundred and two measures of treatment burden or associated concepts were identified. Four direct measures and two indirect measures of treatment burden were assessed, using adapted established criteria, for suitability for use within the dialysis population. The researchers outlined eight key dimensions of treatment burden: medication, financial, administrative, lifestyle, health care, time/travel, dialysis-specific factors, and health inequality. None of the measures adequately assessed all dimensions of treatment burden.

Conclusion: Current measures of treatment burden in dialysis are inadequate to capture the spectrum of issues that matter to patients. There is a need for dialysis-specific burdens and health inequality to be assessed when exploring treatment burden to advance patient care.

KEYWORDS

dialysis, health inequality, measures, scoping review, treatment burden

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INTRODUCTION

Treatment burden is a broad and multifaceted concept. It has been defined as 'a patient's perception of the aggregate weight of the actions and resources they devote to their health care, including difficulty, time and out-of-pocket costs dedicated to the health care tasks such as adhering to medications, dietary recommendations, and self-monitoring' (Boyd et al., 2014, p.2). Sav et al. (2017) present a conceptual framework outlining six key dimensions of treatment burden: financial, medication, administrative, lifestyle, health care and time/travel.

Dialysis is a life-sustaining treatment central to the management of people living with advanced kidney disease. Despite its obvious benefits, dialysis treatment is also extremely burdensome (Roberti et al., 2018). Patients receiving in-centre haemodialysis are required to travel for thrice-weekly sessions, each lasting between 3 and 5 h. Most patients need needles inserted into the forearm vessels for access to the circulation, at each dialysis session. Distressing symptoms including cramps and dizziness are common during sessions, and post-dialysis fatigue even more common (Caplin et al., 2011). Patients receiving peritoneal dialysis face the burden of managing their own exchanges on multiple occasions daily (Jacquet & Trinh, 2019). For patients across both dialysis modalities, there are large amounts of medication and restrictions to diet and fluid intake. All these factors impact on patients' ability to work and socialise, resulting in poor quality of life (Finnegan-John & Thomas, 2013).

Additionally, it is recognised that experience of kidney care is unequal, often referred to as health inequality (Kidney Research UK, 2018; Purcell et al., 2023)—a term used to describe differences that are reasonably avoidable and inequitable between health experience and outcomes across different groups of people (Williams et al., 2022). Research suggests that factors related to the social determinants of health and wider social, economic and demographic factors can comprise patient experience and outcomes. Such factors can include education, deprivation, sex, age, identifying with a minority ethnic heritage or the intersection of any such factors (Kidney Research UK, 2018; Purcell et al., 2023). As a result, there are reasons to believe that dialysis-related burden will be experienced differentially across patients facing varying life circumstances. The Dahlgren-Whitehead model of social determinants of health highlights five levels of influence on health: personal characteristics, individual lifestyle factors, social and community networks, living and working conditions, and general socioeconomic, cultural and environmental conditions (Dahlgren & Whitehead, 2007). In the United Kingdom and other health settings, there is clear evidence of social, economic, cultural and demographic factors being associated with a range of kidney health inequalities. For example, people from South Asian and Black heritage backgrounds are three to five times more likely to start dialysis than their White heritage counterparts (Kidney Research UK, 2018). They are also less likely to receive a transplant so spend more time contending with treatment burden on dialysis (Kidney Research UK, 2018). Similarly, patients from areas of high

deprivation are more likely to commence in-centre haemodialysis than to receive peritoneal dialysis (Kidney Research UK, 2018). The latter may offer advantages that reduce treatment burden (Antoun et al., 2022). It is important therefore to consider factors related to health inequality when assessing burden of treatment within the dialysis population. Such life circumstances may exacerbate the challenges related to treatment perception and overall burden and so it is important for these to be assessed as part of a broader agenda to help tackle treatment burden for dialysis patients.

The Standardised Outcomes in Nephrology—Haemodialysis (SONG-HD) initiative has identified factors such as dialysis-free time, ability to work and travel, and impact on family and friends as 'critically important' for the majority of patients receiving haemodialysis (Evangelidis et al., 2017). It has also been recommended that treatment burden be included in clinical practice guidelines (Dobler et al., 2018). Despite this, there are very few tools available to measure burden of treatment in chronic illness, and even fewer to assess treatment burden within the dialysis population specifically. Aspects of treatment burden are often measured as part of broader patient-reported outcome measures, or implied through other related outcomes such as disease burden, symptom burden, and quality of life (Eton et al., 2013).

Eton et al. (2013) conducted a systematic review of instruments used to measure treatment burden in three chronic diseases including chronic kidney disease (CKD). Six measures used in CKD were described, though they focused on specific constructs such as distress, barriers to self-care and treatment satisfaction, rather than assessing treatment burden in its entirety.

Sav et al. (2017) undertook a scoping review of treatment burden measures in chronic disease. They found that the majority of studies reporting direct measures of treatment burden were qualitative. Some quantitative studies directly measured treatment burden in specific diseases such as cancer and diabetes, but not CKD. Two generic measures of treatment burden, the Treatment Burden Questionnaire (TBQ; Tran et al., 2014) and Patient Experience with Treatment and Self-management (PETS; Eton et al., 2017) were identified. Whilst these measures are commonly used within health research, it is unclear to what extent they are suitable for use within the dialysis population. Therefore, the aim of this scoping review was to identify generic and disease-specific measures of treatment burden in CKD, and assess their suitability for use within the dialysis population. This would help to progress the appropriate and accurate use of patient reported outcomes for developments in kidney care delivery.

METHODS

Protocol and registration

This scoping review has been reported in accordance with the PRISMA extension for scoping reviews (PRISMA-ScR; Tricco et al., 2018). The study protocol was preregistered with Open

Science Framework (Registration [Doi:10.17605/OSF.IO/9SF4J](https://doi.org/10.17605/OSF.IO/9SF4J)). Due to the lack of disease-specific treatment burden measures identified in a preliminary search, an additional search was conducted to also include generic measures of treatment burden.

Search strategy

The initial search for disease-specific measures was performed on July 25, 2022 and was rerun on 13th December 2022. The aim of the search was to identify studies reporting on treatment burden or associated concepts (e.g., quality of life, disease burden, symptom burden, caregiver burden) in the CKD population. The search was conducted using CINAHL, MEDLINE and Cochrane Library databases. Search terms were generated around three main concepts: 'Chronic Kidney Disease', 'Treatment Burden' and 'Measure'. The search was limited to sources written in the English language. No date restrictions were applied. The full search strategy can be found in Supporting Information S1.

In relation to generic measures of treatment burden, the researchers examined the scoping review conducted by Sav et al. (2017) which provided an overview of treatment burden measures in chronic disease. The researchers used the search terms reported by Sav et al., 2017; ('treatment burden' OR 'burden of treatment' OR 'medication burden' OR 'burden of medication' OR 'treatment experience' OR 'time burden' OR 'workload burden' OR 'cost of illness' AND 'chronic disease') to identify other generic measures of treatment burden which may have been developed since the publication of the Sav et al. review in 2017. The updated search was conducted in MEDLINE, CINAHL and Scopus and was limited to articles published between 2016 and 2022.

Study selection and data extraction

Eligibility criteria were constructed using the PCC Framework (Peters et al., 2017). Studies were initially included if they described the development, validation or use of a treatment burden measure or associated concept measures in patients with CKD over the age of 18 years old. Associated concepts included treatment satisfaction, quality of life, illness intrusiveness, disease burden, symptom burden and caregiver burden. A full overview of the inclusion and exclusion criteria can be found in Table 1.

Search results were extracted into a reference management tool Rayyan (Ouzzani et al., 2016), and duplicate articles removed. The first author (EC) screened the sources via their title and abstract to identify and remove studies that did not meet the inclusion criteria. Full-text screening of remaining sources was then performed to determine their eligibility for inclusion in the review. A subsection of sources were independently assessed by EV and KF. Conflicts were resolved through discussion with the research team. Data extraction of key information, including author, year of publication, type of population (e.g., predialysis, dialysis, transplant, conservative care and chronic illness), outcomes of interest (e.g., treatment burden, treatment satisfaction, quality of life etc.) and the outcome measures used (e.g., TBQ, Kidney Disease Quality of Life Questionnaire), was then completed.

The list of included sources was then further refined to only include those reporting the development, validation or use of explicit treatment burden measures in patients receiving dialysis for advanced kidney failure. Dialysis modalities included haemodialysis, haemodiafiltration and peritoneal dialysis. The researchers compiled a list of the treatment burden measures in these studies, and the original articles describing the development of each tool was sought.

TABLE 1 Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
<i>Disease-specific</i>		
Population	Adults patients (≥ 18 years old) with chronic kidney disease.	Children (< 18 years old)
Concept	Describing the development, validation or use of a patient-reported measure of treatment burden (or associated concept ^a).	Measuring the global, national, or regional burden of disease.
Context	Written in English.	N/A
<i>Generic</i>		
Population	Adults patients (≥ 18 years old) with one or more chronic condition.	Children (< 18 years old) Patients with one or more acute medical condition.
Concept	Describing the development, validation or use of a patient-reported measure of treatment burden (or associated concept ^a).	Measuring the global, national, or regional burden of disease. Describing the development, validation or use of a patient-reported measure of treatment burden (or associated concept) for specific health conditions (e.g., diabetes).
Context	Written in English. Published between 2016–2022.	Published pre-2016.

^aAssociated concepts include: treatment satisfaction, quality of life, illness intrusiveness, disease burden, symptom burden and caregiver burden.

In this instance, the extracted data included: Source characteristics (e.g., study title, study authors, year of publication) and measure characteristics (e.g., title of measure, number and name of domains, number of items, items, method of scoring, reliability measures, validity measures and population in which the measure was used).

For the generic treatment burden aspect of the study, sources were included if they described the development, validation or use of a direct treatment burden measure in adult patients (>18 years old) with one or more chronic condition. Sources were excluded if they included measures for specific health conditions (Table 1). The same data extraction process used for the disease-specific search was applied to the generic search.

Synthesis of results

The characteristics of included measures were summarised narratively. The measures of treatment burden were reviewed in terms of their reliability (internal consistency and test-retest reliability) and validity. Internal consistency reliability was assessed using Cronbach's alpha—a value > 0.7 indicate good internal consistency reliability. Test-retest reliability was assessed using intraclass correlation coefficient (ICC) values. ICC values of <0.5 indicate low test-retest reliability, between 0.5 and 0.75 moderate reliability, between 0.75 and 0.9 good reliability and values > 0.9 indicate excellent reliability (Koo & Li, 2016). Validity was determined by exploring whether scores on the treatment burden scales were associated with scores from tools measuring related constructs, or whether scores differed between populations known to experience different levels of treatment burden.

To be suitable for use within the dialysis population, treatment burden measures need to address all dimensions of treatment burden. Sav et al. (2017) have outlined six key dimensions of treatment burden: medication, financial, administrative, lifestyle, health care and time/travel. Burdens specifically related to dialysis treatment have been identified in the literature and were also included as dimension of treatment burden in the current review. Dialysis-specific burden include: intra- and post- dialytic symptoms, maintenance of catheter/access sites, and needling procedures (Karamanidou et al., 2014; Shahrokhi et al., 2014). To determine the suitability of each treatment burden measure, items were labelled according to the dimension of treatment burden they address. Measures needed to include at least one item addressing each dimension of treatment burden to be considered suitable for use with the dialysis population. In addition, the research team considered health inequality as a distinct, research informed aspect of the burden of dialysis treatment. Within this, the researchers explored the extent to which each measure or treatment burden framework was developed with input from a diverse range of patients in terms of their demographic attributes, and how far wider social, economic, and cultural influences on health had been considered within each tool. The researchers were guided by the principle that patient experience of treatment burden is more

usefully understood by capturing contextual information pertaining to patients' life circumstances.

RESULTS

Selection of sources of evidence

A total of 5034 sources were identified in the search for disease-specific measures of treatment burden and related concepts. Five hundred and seventeen sources were eligible for data extraction. Of the 100 measures which were identified from this search, only two explicitly measured treatment burden: the Haemodialysis Stressor Scale (HSS; Murphy et al., 1985) and the PETS Questionnaire (Eton et al., 2017).

The search for generic treatment burden measures identified 1350 sources. Following the removal of duplicates ($n = 534$) and ineligible sources ($n = 789$), 27 sources were included for data extraction. Three generic measures of treatment burden were extracted: the Treatment Burden Questionnaire (TBQ; Tran et al., 2014), the Multimorbidity TBQ (MTBQ; Duncan et al., 2020) and the PETS questionnaire as identified above.

Very few studies assessed burden of treatment in the CKD population using explicit treatment burden measures. Instead, levels of treatment burden were often implied through quality of life scores or illness-related outcomes such as illness intrusiveness and disease burden. As a result, the most relevant and frequently used indirect measures of treatment burden were also included in this study: the Kidney Disease Quality of Life—36 Item Survey (KDQoL-36; Hays et al., 1994) and Illness Intrusiveness Rating Scale (IIRS; Devins, 2010).

A PRISMA flow diagram outlining the selection process can be found in Figure 1.

Characteristics of potential treatment burden measures

Disease-specific treatment burden measures

HSS

The HSS is a 29 item questionnaire which measures the perceived frequency and intensity of stressors associated with haemodialysis treatment for advanced kidney failure. The scale has two subscales: (1) Physiological stressors (six items) and (2) Psychosocial stressors (23 items). Responses are rated on a 5-point Likert scale ranging from 1 ('Not at all stressed') to five ('Stressed a great deal'). An overall stressor score can be generated by summing the scores for each individual item to create an overall score ranging from 29 to 116. Higher scores on the scale represent a greater severity of haemodialysis stressors.

The HSS has been evaluated within the US dialysis population. The HSS had a good internal consistency (Cronbach $\alpha = .89$), and a

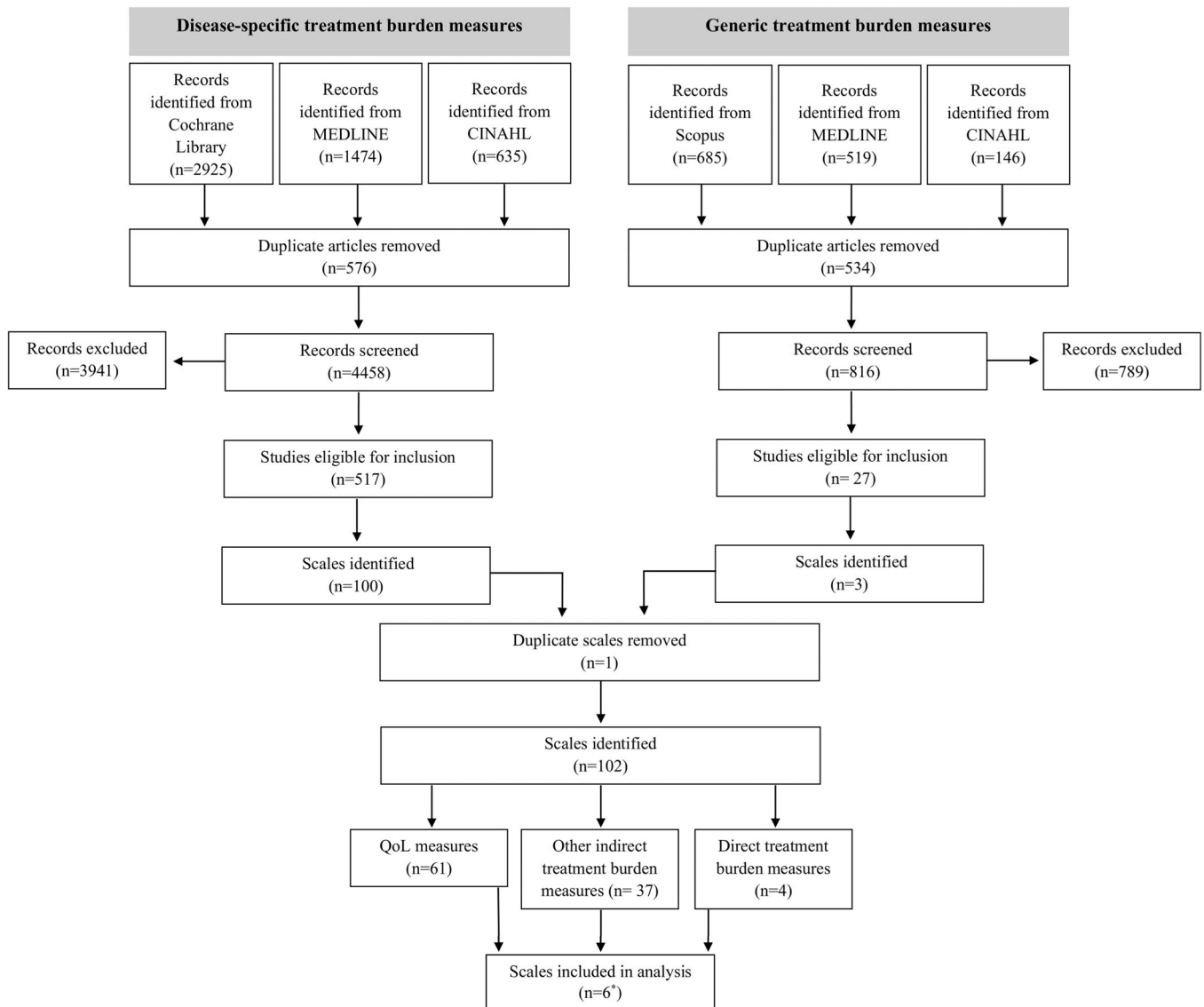


FIGURE 1 Study selection PRISMA flow diagram. *four direct measures of treatment burden and the two most frequently used and relevant indirect measures.

moderate test–retest reliability (ICC = 0.71; Baldree et al., 1982). Due to the novelty of classifying dialysis stressors as physiological versus psychological when the scale was developed, construct validity was assessed through factor analysis. Factor analysis revealed insufficient support for the dichotomous classification of dialysis stressors, instead indicating that a three-factor solution (characterising items as psychobiological, psychosocial or dependency/restriction stressors) may be more appropriate (Murphy et al., 1985).

KDQOL-36

The KDQOL-36 is a 36 item measure of kidney disease quality of life, derived from the Kidney Disease Quality of Life (KDQoL) questionnaire (134-items). The KDQoL-36 consists of four subscales: (1) SF-12 [Physical Component Summary (PCS; 12 items) and Mental Component Summary (MCS; 12 items)], (2) Burden of Kidney Disease

(four items), (3) Symptoms/problems of Kidney Disease (12 items), and (4) Effects of Kidney Disease (8 items). Raw scores for each item are computed and transformed into a 0–100 range, with higher scores representing higher quality of life.

The original 134-item KDQoL questionnaire has demonstrated good reliability and validity. The psychometric properties of the KDQoL-36 have received relatively little assessment in the United Kingdom. Peipert et al. (2018) examined the reliability and validity of the KDQoL-36 kidney-specific subscales in a sample of US dialysis patients. In their study, the three kidney-specific scales all demonstrated good internal consistency (Cronbach $\alpha \geq .80$). Each subscale was also positively correlated with scores on the SF-12 PCS and MCS, indicating good construct validity. KDQoL-36 scores differed significantly between dialysis modality, with patients on PD reporting greater health-related quality of life than patients on HD.

IIRS

The IIRS is a 13 item scale assessing illness intrusiveness. Illness intrusiveness represents the disruption caused by a disease and/or its treatment. Respondents are asked to rate the degree to which their illness and/or its treatment interfere with different aspects of their life (e.g., health, work, relationship with partner). Responses are recorded on a 7-point Likert scale ranging from 1 ('not very much') to 7 ('very much'). An overall illness intrusiveness rating score can be generated by summing the scores for each individual item to create a total score ranging from 13 to 91, with higher scores indicating greater illness intrusiveness.

The IIRS has been used in a variety of chronic conditions. In advanced kidney failure, the IIRS had a good internal consistency (Cronbach $\alpha = .82$) and test-retest reliability (ICC = 0.79). A vast amount of research has been conducted supporting the validity of the IIRS. Of particular interest, Devins (2010) found that IIRS scores differed between patients receiving dialysis (Haemodialysis and Continuous Ambulatory Peritoneal Dialysis) and those who had received a kidney transplant, with patients on dialysis reporting higher IIRS scores. IIRS scores also differed across different stages of CKD, with patients who do not yet require renal replacement therapy reporting lower IIRS scores than patients on dialysis (Devins, 2010).

Generic treatment burden measures

PETS. The PETS is a 48 item questionnaire measuring the burden of chronic illness treatment and self-care. The PETS consists of nine domains: (1) Medication information, (2) Medications, (3) Medication appointments, (4) Monitoring health, (5) Interpersonal challenges, (6) Medical expenses, (7) Difficulty with health care services, (8) Role activity limitations, and (9) Physical and mental exhaustion. Each item is scored on a 4- or 5-point Likert scale. The raw scores for each item can be computed and transformed into a 0–100 range, with higher scores indicating greater treatment burden.

Evaluation of the PETS was conducted using a sample of US patients with chronic disease (e.g., hypertension, lipid metabolic disorders). Cronbach's alpha ranged from 0.79 to 0.95 across all nine scales, demonstrating good internal consistency. In regard to validity, PETS scores were positively correlated with scores on the Chronic Condition Distress Scale and the Treatment Satisfaction Questionnaire for Medications side effects scale (TSQM-Side effects). Scores were negatively correlated with medication convenience, self-efficacy and mental health. Higher scores on the PETS were also associated with poor medication adherence, lower health literacy and greater financial difficulties (Eton et al., 2017).

TBQ. The TBQ is a 15 item questionnaire measuring treatment burden for patients with one or more chronic condition. Respondents are asked to rate the burden of health care activities such as taking medication, administrative tasks, adhering to advice on diet and physical activity, and the impact of their health care on their relationships with others. Each item is rated on a 10-point Likert scale ranging from 0 ('Not at problem') to 10 ('Big problem'). An overall treatment burden score can be

generated by summing the scores for each individual item to create a total score ranging from 0 to 150, with higher scores indicating greater treatment burden.

The TBQ was evaluated in a sample of patient with chronic disease (e.g., neurological disease, psychiatric disease, rheumatologic disease etc.). The TBQ had a good internal consistency (Cronbach $\alpha = .90$) and test-retest reliability (ICC = 0.77; 95% confidence interval: 0.70–0.82). The questionnaire also demonstrated good construct validity. TBQ global scores were negatively correlated with quality of life. Higher scores on the TBQ were associated with poor medication adherence and a lack knowledge from patients regarding their condition and treatment. TBQ scores were positively correlated with clinical variables such as the number of conditions, number and frequency of medications, number of medical appointments and number of hospitalisations (Tran et al., 2014).

MTBQ. The MTBQ is a measure of treatment burden in patients with multimorbidity. The MTBQ consists of 10 main items, in addition to three optional items which may be relevant to certain populations. Respondents are asked to rate the extent to which they experience difficulty with health care tasks such as talking lots of medications, monitoring their medical conditions, making lifestyle changes and arranging appointments. Each item is rated on a 4-point Likert scale ranging from 0 ('Not difficult/does not apply') to 4 ('Extremely difficult').

The MTBQ has been evaluated in English and Scottish patients with multimorbidity (≥ 3 conditions). The MTBQ had good internal consistency both for the 10-item questionnaire (Cronbach $\alpha = .83$), and when all optional questions were included (Cronbach $\alpha = .84$). Scores on the MTBQ were positively associated with scores on the Health Care Task Difficulty scale, the Bayliss disease burden scale, and with the number of self-reported comorbidities. The MTBQ was negatively associated with quality of life and self-reported health (Duncan et al., 2020).

Assessment of the suitability of potential treatment burden measures for use in dialysis

None of the measures identified in this review addressed all dimensions of treatment burden. The three generic treatment burden measures (PETS, TBQ, and MTBQ) addressed the six dimensions of treatment burden proposed by Sav et al. (2017), but did not include any items related to dialysis-specific burden. The HSS and KDQOL-36 were the only measures identified in this review to include questions specific to dialysis. The IIRS addressed the fewest dimensions of treatment burden, with questions primarily focusing on lifestyle and financial factors.

In relation to health inequality, the majority of treatment burden measures used patient experiences to generate survey items, however the extent to which sample characteristics are reported varies between measures. During the initial development of the PETS, researchers intentionally recruited participants from different medical centres to ensure socioeconomic and ethnic diversity within the sample. Among the other measures of treatment burden, specific

data pertaining to sample characteristics were either unavailable or demonstrated a lack of diversity within the sample. Whilst the majority of measures did include items which address financial burden, the extent to which other social, economic, cultural and demographics factors were explored is limited. Further contextual information is required to understand how factors relating to patients' life circumstances (e.g., education level, social networks, and proficiency in the language in which care is delivered) may influence treatment burden.

An overview of the treatment burden dimensions addressed by each measure can be found in Table 2. Strengths and limitations of each measure against the suitability criteria can be found in Table 3.

DISCUSSION

Summary of evidence

The aim of this scoping review was to identify generic and disease-specific measures of treatment burden in CKD, and assess their suitability for use within the dialysis population. Findings suggest that current measures of treatment burden are inadequate as compared to adapted established dimensions of the construct.

Understanding treatment burden is vital for patient care. The Cumulative Complexity Model (Shippee et al., 2012) suggests that imbalances between patients' workloads (e.g., treatment demands, self-care, day-to-day tasks and responsibilities) and their capacity to effectively manage demands can greatly increase treatment complexity and complicate care. Treatment burden substantially influences workload-capacity imbalances (Shippee et al., 2012). For care to be effective, treatment regimens should be minimally disruptive. Interventions to reduce patient workload or increase patient capacity should be considered (Montori, 2019). Comprehensive tools are needed to identify patients who may be experiencing high levels of treatment burden, and to support the development of targeted, minimally disruptive health care interventions that maximise ability to engage with day-to-day life and self-care (May et al., 2009).

Patients receiving dialysis experience high levels of treatment burden due to the complex and time-consuming nature of their treatment regimens. In addition to the six treatment burden dimensions proposed by Sav et al. (2017) the authors considered it important that dialysis-specific burdens (e.g., needling procedures, treatment side-effects) and the burden of health inequality is captured within treatment burden measures for the dialysis population. Our focus on health inequality relates to the finding that not all patients experience their condition, its management, and the associated burden in the same way. This is important to know and factor into considerations about timing interventions and wider attempts at improving patient reported experience.

The six measures identified in this study demonstrated good reliability and validity, however only half included dialysis patients in their evaluation. In addition, the extent to which the measures addressed all aspects of treatment burden, as defined in this study, is

TABLE 2 Dimensions of treatment burden.

Treatment burden measure	Condition	Number of items	Dimension 1: medication	Dimension 2: financial	Dimension 3: administrative	Dimension 4: lifestyle	Dimension 5: health care	Dimension 6: time/travel	Dialysis-specific Dimension	Health inequality Dimension
Haemodialysis stressor scale (HSS)	Advanced kidney failure—Haemodialysis	29	X	✓	X	✓	✓	✓	✓	X
Kidney disease quality of life—36 item questionnaire (KDQOL-36)	Kidney Disease	36	X	X	X	✓	✓	✓	✓	X
Illness intrusiveness rating scale (IIRS)	Advanced kidney failure	13	X	✓	X	✓	X	X	X	X
Patient experience with treatment and self-management (PETS)	Chronic conditions	48	✓	✓	✓	✓	✓	✓	X	X

(Continues)

TABLE 2 (Continued)

Treatment burden measure	Condition	Number of items	Dimension 1: medication	Dimension 2: financial	Dimension 3: administrative	Dimension 4: lifestyle	Dimension 5: health care	Dimension 6: time/travel	Dialysis-specific Dimension	Health inequality Dimension
Treatment burden questionnaire (TBQ)	Chronic conditions	15	✓	✓	✓	✓	✓	✓	X	X
Multimorbidity treatment burden questionnaire (MTBQ)	Multimorbidity	10	✓	✓	✓	✓	✓	✓	X	X

limited. In the majority of CKD studies, levels of treatment burden were implied through scores on related concepts, such as quality of life, illness intrusiveness and medication data (e.g., number of tablets taken per day), rather than being measured explicitly. The KDQoL-36 and IIRS were identified as the most commonly used and relevant indirect measures of treatment burden in patients with CKD. Whilst these measures did include some items addressing aspects of treatment burden, the tools primarily focused on the burden of disease. The HSS was the only disease-specific tool directly measuring treatment burden. The scale focused specifically on the stressors associated with haemodialysis, but did not address administrative or medication burden, which can be significant within the dialysis population. The PETS, TBQ and MTBQ all covered the six treatment burden dimensions proposed by Sav et al. (2017), but did not include any questions specific to dialysis. None of the treatment burden measures included in the review addressed burden associated with health inequality. These findings demonstrate the need for more specific measures to assess burden of treatment in the dialysis population.

Limitations

One limitation of the current review is the particular focus on direct measures of treatment burden. The search strategy used in the review did not include terms relating to individual aspects of treatment burden (e.g., cost of treatment, relationship with health care professionals) so tools assessing these components may not have been included. Nevertheless, findings from a systematic review exploring measures of treatment burden across three chronic diseases corroborates our finding that more tools need to be developed for use within the dialysis population (Eton et al., 2013).

Another potential limitation of the current review is the initial focus on only disease-specific measures of treatment burden. This method was chosen for pragmatic reasons to ensure that only tools relating to kidney disease were included in the search. Treatment burden is largely under-investigated within advanced kidney failure (May et al., 2016), and in the current review substantially fewer kidney disease-specific measures were identified than originally anticipated. The advantage of conducting a scoping review is the ability to explore the topic and identify potential knowledge gaps (Munn et al., 2018). The lack of treatment burden measures for CKD prompted the additional search for generic measures which could then be applied to the target population.

Implications for clinical practice

Assessing burden of treatment is hugely important in the selection and management of dialysis treatment regimens, yet there are currently no tools that fully address the burden of dialysis. Having an appropriate measure of treatment burden could have a substantial impact on clinical practice in facilitating decision-making for changes to modality and/or dialysis prescription, as well as encouraging access

TABLE 3 Strengths and limitations of treatment burden measures.

Treatment burden measure	Strengths	Limitations
Haemodialysis stressor scale (HSS)	Population specific. Good reliability. Includes items addressing burden related to financial, lifestyle, health care, time/travel, dialysis-specific issues.	Further assessment of validity needed. Does not include items addressing burden related to medication, administrative, health inequality issues. Items generated from literature and dialysis nurse experts. No patient input.
Kidney disease quality of life—36 item questionnaire (KDQOL-36)	Designed for population with kidney disease. Good reliability and validity. Includes items addressing burden related to lifestyle, health care, time-travel, dialysis-specific issues.	Does not explicitly measure treatment burden. Does not include items addressing burden related to medication, financial, administrative, health inequality issues. Diversity of patient participants unclear.
Illness intrusiveness rating scale (IIRS)	Designed for use in kidney disease/HD. Good reliability and validity. Includes items addressing burden related to financial and lifestyle burden issues.	Does not include items addressing burden related to medication, administrative, health care, time/travel, dialysis-specific, health inequality issues. Diversity of patient participants unclear.
Patient experience with treatment and self-management (PETS)	Good reliability and validity. Includes items addressing burden related to medication, financial, lifestyle, health care, time/travel. Diverse validation set.	Generic measure. Does not include items addressing burden related to dialysis-specific and health inequality issues.
Treatment burden questionnaire (TBQ)	Good reliability and validity. Includes items addressing burden related to medication, financial, administrative, lifestyle, health care, time/travel issues.	Generic measure. Does not include items addressing burdens related to dialysis-specific, health inequality issues. Diversity of patient participants unclear
Multimorbidity treatment burden questionnaire (MTBQ)	Good reliability and validity. Includes items addressing burden related to medication, financial, administrative, lifestyle, health care, time/travel issues.	Generic measure. Does not include items addressing burdens related to dialysis-specific, health inequality issues. Little diversity in patient participants.

to interventions that address specific aspects of patient reported experience. In this review, the potential for expanding the concept of treatment burden has also been proposed to help researchers and clinicians further consider important aspects of kidney health inequality. The drivers of health inequality in this context are well defined, and cannot be separated from treatment burden itself.

CONCLUSION

Current measures of treatment burden in dialysis are inadequate. The researchers suggest that dialysis-specific burdens and health inequalities should be assessed when exploring treatment burden in this population. Future research should focus on the development of new measures of treatment burden, with particular input from patients about the specific health care tasks associated with dialysis treatment.

AUTHOR CONTRIBUTIONS

Emma Caton participated in the design of the study and helped with the collection, extraction, analysis, and interpretation of data. Shivani Sharma participated in the design of the study and helped with data interpretation. Enric Vilar conceptualised the study, participated in

the design of the study and helped with the collection, extraction, analysis, and interpretation of data. Ken Farrington conceptualised the study, participated in the design of the study, and helped with the collection, extraction, analysis, and interpretation of data. All authors contributed to and approved the final manuscript.

CONFLICT OF INTEREST STATEMENT

The author declare no conflict of interest.

DATA AVAILABILITY STATEMENT

All relevant data are included within the manuscript.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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