

# BMJ Open Patients' and kidney care team's perspectives of treatment burden and capacity in older people with chronic kidney disease: a qualitative study

Hilda O Hounkpatin <sup>1</sup>, Geraldine M Leydon,<sup>1</sup> Kristin Veighey,<sup>2</sup> Kirsten Armstrong,<sup>3</sup> Miriam Santer,<sup>1</sup> Maarten W Taal <sup>4,5</sup>, Pete Annells,<sup>6</sup> Carl May,<sup>7</sup> Paul J Roderick,<sup>1</sup> Simon DS Fraser <sup>1</sup>

**To cite:** Hounkpatin HO, Leydon GM, Veighey K, *et al.* Patients' and kidney care team's perspectives of treatment burden and capacity in older people with chronic kidney disease: a qualitative study. *BMJ Open* 2020;**10**:e042548. doi:10.1136/bmjopen-2020-042548

► Prepublication history and additional material for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2020-042548>).

Received 07 July 2020  
Revised 17 October 2020  
Accepted 16 November 2020



© Author(s) (or their employer(s)) 2020. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

## Correspondence to

Dr Hilda O Hounkpatin;  
H.O.Hounkpatin@soton.ac.uk

## ABSTRACT

**Objective** Chronic kidney disease (CKD) is often a multimorbid condition and progression to more severe disease is commonly associated with increased management requirements, including lifestyle change, more medication and greater clinician involvement. This study explored patients' and kidney care team's perspectives of the nature and extent of this workload (treatment burden) and factors that support capacity (the ability to manage health) for older individuals with CKD.

**Design** Qualitative semistructured interview and focus group study.

**Setting and participants** Adults (aged 60+) with predialysis CKD stages G3–5 (identified in two general practitioner surgeries and two renal clinics) and a multiprofessional secondary kidney care team in the UK.

**Results** 29 individuals and 10 kidney team members were recruited. Treatment burden themes were: (1) understanding CKD, its treatment and consequences, (2) adhering to treatments and management and (3) interacting with others (eg, clinicians) in the management of CKD. Capacity themes were: (1) personal attributes (eg, optimism, pragmatism), (2) support network (family/friends, service providers), (3) financial capacity, environment (eg, geographical distance to unit) and life responsibilities (eg, caring for others). Patients reported poor provision of CKD information and lack of choice in treatment, whereas kidney care team members discussed health literacy issues. Patients reported having to withdraw from social activities and loss of employment due to CKD, which further impacted their capacity.

**Conclusion** Improved understanding of and measures to reduce the treatment burden (eg, clear information, simplified medication, joined up care, free parking) associated with CKD in individuals as well as assessment of their capacity and interventions to improve capacity (social care, psychological support) will likely improve patient experience and their engagement with kidney care services.

## INTRODUCTION

Chronic kidney disease (CKD) affects approximately 30% of individuals over 65 in the UK.<sup>1,2</sup> Older individuals with CKD frequently

## Strengths and limitations of this study

- Both patients' and kidney care team members' perspectives of treatment burden and capacity are explored to identify differences and areas for improvement.
- The study included patients from a range of socioeconomic status, geographical location and chronic kidney disease (CKD) severity stages recruited via both primary and secondary care to capture a broad range of perspectives.
- Primary care clinicians and other specialists involved in the care of patients with CKD were not included in this study.
- Study participants were predominantly of white ethnicity.

have multiple long-term conditions, each requiring management such as arranging and attending appointments, having tests and taking medications.<sup>3–6</sup> This demand and its impact on health and well-being has been called 'treatment burden'.<sup>7–9</sup> Individuals with mild to moderate CKD (stages G1–G3a) are usually managed in primary care in the UK and may experience more treatment burden from comorbidities than from their CKD.<sup>4,10</sup> Progression to stage G3b–G5 may lead to new symptoms and new disease management requirements, including lifestyle change, greater clinician involvement from multiple specialities and more frequent monitoring.<sup>11–15</sup> Care demand from each condition interacts to increase workload on patients, potentially outweighing patient 'capacity' (ie, their ability to manage workload created by both treatment/management regimens and the demands of everyday life) and risking treatment failure.<sup>7–9</sup>

Demands on patients who require renal replacement therapy (RRT) are well

documented, but less is known for CKD not requiring RRT.<sup>14–17</sup> Better understanding of patients' and healthcare providers' views on treatment burden, capacity and how these differ is needed to develop effective interventions, both at the individual care and at health system/service level.<sup>18–20</sup> This is particularly important in the context of an ageing population: older people with CKD are more likely to experience greater burden of treatment due to existing comorbidities (eg, multiple medication, adverse drug effects), and may have reduced capacity to manage their conditions.<sup>4 17</sup> We aimed to explore patients' and kidney care team's perspectives on the nature and experience of treatment burden and capacity for older individuals with stages G3b–5 CKD, not currently requiring RRT.

## METHODS

### Participant selection

The reporting of this study is based on the Consolidated Criteria for Reporting Qualitative Health Research.<sup>21</sup>

Participants who were previously diagnosed with CKD (stages G3b–5) were recruited from two general practitioner (GP) practices and two renal clinics in southern England. Participants recruited in primary care were identified through a search of GP practice lists for a coded diagnosis of CKD (estimated glomerular filtration rate (eGFR) <45) and then sent postal invitations to participate, from their GP. Participants recruited through secondary care were initially approached by local consultant nephrologists (KA and KV) during attendance at routine renal outpatient clinics to establish interest in participating.

Participants were purposively sampled to allow diverse characteristics in terms of age, gender, comorbidities and residential area deprivation. Interested participants were screened for inclusion (aged 60+ with CKD stages G3b–5) and exclusion criteria (patients with terminal illness, those unable to give informed consent, and patients with CKD stage G5 due to start RRT in the next 3 months). Sample characteristics were monitored to ensure diversity.

A secondary care multiprofessional kidney team focus group was conducted in a large National Health Service (NHS) hospital trust that includes the local tertiary renal centre for a wide geographical area in southern England. Convenience sampling was used to identify and invite members for the focus group; KV and KA distributed the study information through local networks. Inclusion criterion was any health professional working as part of a kidney care team. We aimed to include representation from each main role (eg, nephrologists, pharmacists, administrator) within the core kidney care team. Exclusion criteria included retired health professionals and health professionals that did not work with patients with CKD.

### Data collection

All participants were given information sheets explaining the study aims. Written informed consent was obtained in

### Box 1 Topic guide for patient interviews

Questions explored participants' understanding of chronic kidney disease (CKD), CKD stage, comorbid conditions and treatment burden issues. These included key potential drivers of burden identified from the existing literature, for example, the demands of medication, changes perceived to have arisen from CKD progression, general practitioner and hospital visits (renal and non-renal), the perceived burden of making lifestyle changes according to advice, and the demands of self-management tasks (including monitoring blood pressure, eg). It also included questions on issues that may help ease the burden and enhance capacity, such as social support, better access to clear information about how to manage their health and improved communication. Information about current support and facilitators and barriers to enable medication adherence and attendance at all scheduled appointments were explored in relation to perceived treatment burden. Basic demographic information, including age, education level, and marital status, was also recorded during interviews. Full interview guide is available in online supplemental appendix.

the patient interviews and kidney team focus group. Interviewers and facilitators were not known to patient interviewees and kidney care team, respectively. Interviews with patients were chosen to explore individual experiences of CKD in depth, while a focus group discussion with health professionals was chosen to generate kidney care team's views and understand areas of contention/consensus.

The interview guide explored how people manage their conditions and how they feel management impacts on daily living (box 1). The interview guide was reviewed by an experienced qualitative researcher (GL) and refined prior to the first interview and again after the first two interviews. HH (female researcher) and SF (male academic with past experience as a GP) conducted semi-structured interviews. The interviews were conducted by telephone or face to face, at the participant's home, to accommodate participant preference and lasted approximately 1 hour.

The focus group topic guide explored the beliefs and experiences of professionals about treatment burden, its causes and associations (box 2). The guide was developed based on findings from the relevant literature and early findings from patient participant interviews and refined through discussions with GL. SF facilitated the kidney care team focus group. The focus group was conducted at participants' place of work (an NHS hospital) and lasted for 1 hour.

### Box 2 Topic guide for focus group

The design of the focus group topic guide incorporated insights from the literature, early findings from patient interviews and questions to directly address the research question. Discussions included exploration of their perception of how people manage their conditions, the requirements of investigations, treatment and monitoring at different chronic kidney disease stages and views on factors that may optimise support for patients to help them manage identified burdens. Full topic guide is available in online supplemental appendix.

Interviews and the focus group discussion were digitally recorded and transcribed verbatim by a professional transcription company. Thematic analysis suggested saturation had been reached by interview 26. Female participants were recruited for a subsequent three interviews to achieve a better gender balance. Local nephrologists were also asked to introduce more patients from ethnic minority backgrounds to the study, although this did not result in an improvement in recruitment of non-white participants.

### Data analysis

SF and HH undertook thematic analysis.<sup>22</sup> Each transcript was read repeatedly and coded in detail, generating and reviewing a list of codes and themes. A draft coding frame was developed and agreed on by team members with qualitative expertise (GL and CM). NVivo V.12 software was used to organise codes and themes. Initial themes and subthemes were developed and refined through discussion with the research team. It was identified retrospectively that the findings fitted with the burden of treatment theory, which was then used to inform the analysis.<sup>8</sup> Use of NVivo, sharing transcripts and group data discussions supported a systematic and transparent approach to working with data and ensured final themes were robust. Interviewers' fieldwork notes were consulted during analysis to ensure the 'live' reflections captured during fieldwork were available to analysts to aid final interpretations.

Interview transcripts and the focus group transcript were analysed separately. A table consisting of a list of themes and subthemes generated from interviews with patient participants was prepared. A similar table was prepared for the focus group discussion and compared with that of the interview.

### Patient and public involvement

A patient with CKD was engaged throughout the project. At the application stage, the patient and public involvement (PPI) representative provided advice on the plain English summary and other aspects of the research, such as consideration of variation between clinicians/units, the importance of adherence to treatments, the potential long period of time that people may spend predialysis, the challenges of repeat prescriptions and changing prescriptions and the importance of the ethos/culture of clinical departments. Over the course of the study, he reviewed study materials such as information for patient participants, advised on draft interview guides and focus group topic guides, provided input on the interpretation of the findings and reviewed the manuscript. He is listed as a coauthor on the manuscript. Our PPI representative is similar to our study population in terms of age group, experience of CKD, geographical location.

## RESULTS

Eleven patients were recruited from two primary care practices and 18 from two renal outpatient clinics. Mean

**Table 1** Characteristics of patient participants

	N	% of total*
<b>Recruitment</b>		
Primary care	11	38
Secondary care	18	62
<b>Sex</b>		
Male	16	55
Female	13	45
<b>Age</b>		
60–69	7	24
70–79	13	45
80–89	9	31
<b>Ethnicity</b>		
White	28	97
Asian	1	3
<b>Highest education attainment</b>		
Secondary school	14	48
Apprenticeship or other postsecondary school training	8	27
Degree	7	25
<b>Marital status</b>		
Married	19	66
Single	2	7
Cohabiting partner	2	7
Widowed	4	14
Divorced	2	7
<b>CKD stage</b>		
3a	1	4
3b	10	34
4	12	41
5	6	21

CKD, chronic kidney disease.

age was 75 (range: 61–89). Most patients were of white ethnicity and CKD stage G3b or 4 (table 1). The focus group comprised two consultant nephrologists, four renal specialist nurses, two renal dieticians, one renal pharmacist and one multidisciplinary team coordinator and outpatient administrator. Focus group members were predominantly female (table 2).

### Treatment burden

Treatment burden was interpreted as the work associated with negotiating healthcare and self-management of health could be understood through three intersecting themes: (1) understanding CKD, its treatment and consequences, (2) adhering to treatments and management advice, (3) interacting with friends, family and health professionals. Table 3 compares subthemes from patient interviews and the focus group discussion. Illustrative

**Table 2** Characteristics of kidney care team members

	N	% of total*
<b>Sex</b>		
Male	1	10
Female	9	90
<b>Ethnicity</b>		
White	10	100
<b>Occupation</b>		
Consultant nephrologist	2	20
Renal specialist nurses	4	40
Renal dieticians	2	20
Renal pharmacist	1	10
Multidisciplinary team coordinator/ outpatient administrator	1	10

quotations from patients and kidney team members are presented in the text.

### Understanding CKD, its treatment and consequences

Some patients described feeling they were given insufficient information about CKD, even when they had asked for more information. Many were uncertain what they should be doing to manage their condition and felt that the coexistence of other conditions complicated this further.

I don't know whether you have to eat differently or whether you drink. I take an awful lot of tablets. So that's probably what's doing it, because I have high blood pressure. (Patient 16, female, CKD 5)

Others, particularly those recruited in secondary care, described the work of learning about the function of the kidneys and the investigations to check kidney function and outcomes of CKD. Many used the internet, leaflets and spoke with specialists to improve their understanding of CKD and its management, while a few relied only on what health professionals told them.

When I first got the kidney disease, I did look online a lot. For instance the kidney biopsy...I had the report and I looked up some of the things there to find out what they meant (Patient 17, female, CKD 3b)

Those who undertook self-directed research to gather information about CKD or spoke to specialists (eg, dietician) described challenges such as receiving conflicting advice.

They [Dieticians] sent me a list of foods which I shouldn't really have, because of the potassium levels and acidic levels. But then I received a bigger pamphlet, and some of the things in it seemed to go against what the first pamphlet said. (Patient 9, male, CKD 5)

Some, mostly secondary care patients, were worried about their condition and future uncertainty. A few talked about planning for the future and wanting to be near a renal unit.

It's not knowing what's going to happen and everything, it's like a waiting game really (Patient 14, female, CKD 5)

Kidney team members also discussed issues with patients receiving conflicting advice from different clinicians and recognised the burden associated with the uncertainty of starting dialysis. However, some felt patients did not always appear to understand the aim or need for treatment and investigations, particularly for earlier CKD stages when patients felt relatively well.

They need a basic understanding of what is going on. They fail to grasp the link between what we're trying to tell them about, what is likely to happen and why we're doing the—initiating the treatments and investigations we're doing and everything else which can be, I think, very much muddled by their comorbidities and what other people have told them'

Loss of or inaccurate information for those not speaking English and attending clinics with friends or relatives to translate for them was highlighted.

The kind of different populations that we're seeing nowadays is growing. If we offer a Polish person an English language sheet, they're like, 'Oh!' Just kind of do what you can with it and kind of get by with your basic interaction

### Adhering to treatments and management

Many patients described the challenges of having to manage and attend many appointments (at different locations), and the time (specifically long waiting times) and effort (eg, arranging transport or difficulty parking).

I just get a bit fed up sometimes of all these visits. In the hospitals the people are wonderful, it's just I'd like someone else to go instead of me. (Patient 20, male, CKD 3b)

Some patients reported challenges of having to take multiple medications, difficulty remembering drug names, or understanding which pills are for which condition, and practical difficulties with handling medication.

So I went into hospital, and when I came out, they gave me two carrier bags full of tablets, and I went to the doctor and I said, 'I don't want all these tablets.' She said, 'Well, if you don't have them, Mrs \*, you'll die.' So she said, 'It's up to you.' So I just said, 'No, I prefer to take them then. (Patient 16, female, CKD 5)

I'm on umpteen pills a day. It seems like the medical profession are very good at saying, oh, take these, plonk, right. You take them, but nobody ever says, I think you're cured of that; you don't need them

**Table 3** Components of treatment burden reported by patients and kidney care team members

	Patients	Professionals
<b>Treatment burden</b>	<b>Understanding CKD, its treatment and consequences</b>	<b>Health literacy issues, language barriers</b>
	<b>Given inadequate information to manage condition</b>	<b>Perceived lack of benefit in medications</b>
	<b>Information gathering</b>	
	Conflicting advice	Conflicting advice
	Anxiety/uncertainty about future	Anxiety/uncertainty about future
	Multimorbidity and polypharmacy adding complexity	Multimorbidity and polypharmacy adding complexity
	<b>Adhering to treatments and management</b>	
	Appointments	Making note/keeping track of multiple appointments
	Travel to appointments/no local care	Travel to appointments/no local care
	Parking	Parking
	Long waiting times	Long waiting times
	Wasted time and effort	Wasted time and effort
	Medication	
	<b>Lack of choice/lack of medication review</b>	
	Remembering names of or distinguishing medications	Remembering names of or distinguishing medications
	Practical difficulties with handling medication	Practical difficulties with taking medication
	<b>Keeping up with changing medication</b>	
	<b>Challenges filling prescriptions</b>	
	Multimorbidity and polypharmacy adding complexity	
	Lifestyle changes	
	<b>Changing diets</b>	
	<b>Bladder issues</b>	
	Difficulty obtaining GP appointments	Difficulty obtaining GP appointments
	Short appointment lengths	
	<b>Unexpected changes to healthcare (eg, being taken off dialysis list)</b>	
	Lack of interpersonal continuity of care	Lack of interpersonal continuity of care
	Communication barriers with health professionals	Communication barriers with health professionals
	<b>Lack of communication and coordination between primary and secondary care</b>	
	Lack of communication and coordination between specialists	Lack of communication and coordination between specialists
		<b>Lack of standardised procedures (eg, different blood forms)</b>

\*Differences in perspectives highlighted in bold.  
CKD, chronic kidney disease; GP, general practitioner.

anymore. You just keep taking these pills, taking these pills, taking these pills (Patient 2, male, CKD 3b)

Some patients reported trouble keeping up with changes in medication and challenges filling prescriptions.

I have to go backwards and forwards between the chemist and the doctors to try and get it sorted out. We just about got that sorted out, and then the manufacturer of the old tablets come back, so I got some of the tablets

that he added plus the new ones that come back on the market. Then I have to dispose of these old tablets, otherwise I get mixed up. (Patient 20, male, CKD 3b)

Many patients, particularly those with CKD stage G4/5, described the difficulties of lifestyle changes, including dietary changes, avoiding certain medications, drinking adequate amounts of water, reducing alcohol and adopting low potassium diets.

I'm supposed to drink eight pints a day for the kidneys which is very difficult, and when you've got a bladder that doesn't hang on, it's very awkward. (Patient 28, female, CKD 4/5)

I could not take anything really because of my kidneys. I had been told by a kidney specialist at the hospital that the only thing I could take for pain was paracetamol. (Patient 5, female, CKD 3b)

Kidney team members generally agreed with patients' reports regarding travel and burden of medication, and long waiting times associated with patient transport services. Multiple members noted the need for more clarity in written communication to patients (eg, clarification of appointment location).

They might have had an hour appointment...and had about a six-hour day.

We see patients throughout the region and they travel up here for various appointments and that is a big thing because they can't understand why they can't have it all done in one place...or on the same day

#### Interacting with others

Most patients described difficulties obtaining appointments with GPs and the short appointment lengths.

I phone up for an appointment, I held it for 10 minutes and I thought this is enough. Then I dialled, held for 10 minutes, another 10 minutes. The last time I did it I rung and I was put straight onto hold and so three min nobody answered put it down. Six times I've done that in a day, one day. (Patient 6, female, CKD 4)

The lack of interpersonal continuity of GP care was highlighted by many. Patients frequently reported seeing a different GP every time and having to explain their health each time.

The GP- because you see a different one every single time- they don't know you from a bar of soap (Patient 8, female, CKD 3b)

Some patients reported communication issues with doctors and nurses including poor bedside manner and difficulties understanding the doctor. Some patients reported lack of communication and coordination between primary and secondary care, and between hospital specialists.

When I met [my nephrologist], she actually said— 'why didn't they contact the renal team here? ...so we could have a joint discussion about what they were proposing and the pros and cons of their treatment recommendation vs what we think you've got on the renal side?' That's not joined up. (Patient 11, male, CKD 3a)

The kidney team discussed the importance of regular, effective communication and building trust to encourage

treatment adherence. Disjointed electronic systems, poor communication between specialties and lack of standardised communication procedures/forms between hospitals were identified as barriers.

They struggle to get that balance right sometimes—which comes down to the communication. It's making sure you've got that regular contact to sort of relieve the anxiety.

We spend a lot of time saying, 'This is important, this is important, this is important' and then they're getting admitted to [ X hospital], and they don't give it [erythropoietin] and they think, well, I've been told this is really important and that causes anxiety

#### Patient capacity

We categorised experienced capacity in three ways: (1) personal attributes/attitudes, (2) support network, (3) financial capacity, environment and life responsibilities. [Table 4](#) presents subthemes of capacity, reported by patients and the kidney team. Illustrative quotations from patients and kidney team members are presented in the text.

#### Personal attributes/attitudes

Some patients described trying to remain positive.

I just sort of try and remain positive...You've got to try and look on the bright side no matter what's happening.' (Patient 4, female, CKD 4)

Many patients reported using organisational skills such as keeping diaries and developing routines to remind when to take medication or attend appointments.

It's just habit, I know I take so many tablets in the morning, another one at lunch time and the others in the evening before I go to bed, it's just a routine. (Patient 27, female, CKD 4)

Some reported setting exercise targets or monitoring their own blood pressure. Some reported using the internet to gather information about their condition, email health professionals, view results, and book GP appointments.

The kidney team also recognised the importance of a positive patient attitude in terms of how they managed their CKD.

It's the glass half-full people who are always looking... 'Yes, okay, this is bad but I'm going to manage it

The kidney team also mentioned other important factors including socioeconomic status, educational level and CKD severity. Specifically, they noted that patients from lower socioeconomic background experienced more difficulty managing their condition whereas patients of higher socioeconomic status with the same conditions found it easier or seemed to have better knowledge of how to access services. Patients with greater CKD severity appeared to have a better understanding of CKD

**Table 4** Components of capacity discussed by patients and kidney care team members

	Patients	Professionals
<b>Capacity</b>	<p><b>Personal attributes/ attitudes</b></p> <p>Trying to be positive/focusing on the positives</p> <p><b>Pragmatic skills: internet use, emailing health professionals, routinising life, setting targets, monitoring blood pressure</b></p> <p><b>Support network</b></p> <p>Family and friends that give emotional and practical support (transport, food, getting medication, health literacy) and motivation</p> <p><b>Restricted social activities due to burden of CKD</b></p> <p><b>Carer support</b></p> <p>Patient transport services</p> <p><b>Patient groups and community support (including 'disease community')</b></p> <p><b>Exercise club</b></p> <p><b>Information sources: clinicians, leaflets, 'patient view'</b></p> <p><b>Prescription delivery</b></p> <p><b>Financial capacity, environment and life responsibilities</b></p> <p>Financial struggles: loss of employment, limited benefits</p> <p><b>Car ownership/ ability to pay for transport to appointments, private treatment</b></p> <p><b>Geographical location: being close to hospitals</b></p> <p><b>Blue badge for disability</b></p> <p><b>Adaptations to home</b></p> <p>Buying equipment to help manage conditions (eg, pain)</p> <p>Carers of dependants</p>	<p>Having a positive attitude</p> <p><b>Demographic characteristics: Level of education, socioeconomic background</b></p> <p><b>Engaging with health professionals and research</b></p> <p>Family and friends that give emotional and practical support</p> <p>Patient transport services</p> <p><b>Specialist input (psychologists, social services)</b></p> <p><b>Friendly, positive experience with kidney care team</b></p> <p>Financial struggles: time off work, costs associated with lifestyle changes (eg, diet), loss of employment</p> <p><b>Geographical location: being close to hospitals</b></p> <p>Carers of dependants</p>

CKD, chronic kidney disease.

and greater belief in treatments, as opposed to patients with early stages of CKD, who may not have symptoms and therefore may be less likely to see the value in treatments.

#### Support network

Many patients reported family members and friends helped with practical issues around disease management, such as cooking, shopping and reminding about, driving to and attending appointments with them. Men, in particular, spoke of the value of having their partner present, including attending appointments and listening to the doctors with them to help them better understand what they needed to do to manage their health.

That's quite useful, because when two people hear the story [what the clinician has said during the appointment] and then you talk about it afterwards, you

pick up things that you might have missed (Patient 18, male, CKD 4)

A few chose not to burden their family, and more specifically children, with their conditions.

I've managed to hide it from my daughter. I wouldn't like my daughter to know, she knows very little about what has happened to me...she's a real worrier. (Patient 20, male, CKD 3b)

Two patients highlighted the need for more 'disease community' groups connecting people with the same condition.

Many reported having to adopt a slower pace of life and limiting activities such as gardening, travel or social engagements.



I have stopped helping with the lunches because I've found that my kidney complaint is making me very, very tired, so I've decided that I've just got to look after myself (Patient 29, female, CKD 5)

Kidney team members generally agreed with patients' reports. Administration staff were identified as an important source of support (taking phone calls, booking suitable appointments, maintaining a friendly atmosphere). Many members discussed the lack of mental health and social services and their potential importance for people with CKD.

Patients ask about specialist input in terms of levels of activity and exercise. They want special advice, psychology. Social workers

#### Financial capacity, environment and life responsibilities

Patients were receiving free care under the NHS. However, some reported paying for private care (eg, for pain management) to avoid long waiting times or buying expensive equipment to help manage pain.

It's a lot of money but I can afford to have it done.

There are people who aren't as well off as I am who can't... I can't imagine being in that situation. That's no choice at all. You're stuck with waiting what will have been almost a year to get the treatment [radiofrequency ablation]. (Patient 22, male, CKD 3b)

Two patients lost employment due to symptom burden and received limited financial support. Some discussed the cost of travel to appointments, and how living nearby, owning a car or having patient transport services helped with this.

Well there's poor and there's rich and they've got cars and go there [hospital] on their own. But as I say, if you haven't got it you can't do it can you? (Patient 6, female, CKD 4)

In addition to managing their health, some patients reported the impact of other life responsibilities such as working and being a carer for family members.

I've spent the last week being online, getting numbers, phoning Fit for Work to see what we can and can't do, phoning—just trying to sort my husband and Granny's appointments, and bathing granny and doing all her washing and our washing. (Patient 8, female, CKD 3b)

Kidney team members acknowledged that caring responsibilities further increased burden and influenced treatment decision. It was agreed that attending appointments, symptom burden, and dietary requirements contributed to financial difficulties.

I think they worry about their health and how they're going to be able to live a life as they have previously done, working, financial commitments, family commitments. They all play a massive part

## DISCUSSION

This study explored patients' and kidney care team's views on the nature and experience of treatment burden and patient capacity for older patients with predialysis CKD. Both patients and kidney team members discussed how patient factors (eg, presence of comorbidities) and healthcare system factors (eg, multiple appointments, communication and coordination issues between hospitals/specialties) influenced treatment burden, which is consistent with the previous literature.<sup>14 23</sup> Both groups considered patient capacity as being dependent on psychological, social and financial/environmental factors, and interacting with treatment burden.

There were some differences in views of treatment burden and capacity according to patient characteristics. Female patients generally appeared to have a better understanding of their renal function and how to manage their health than males. Travel and time spent at appointments and not being able to enjoy hobbies due to their health seemed to be a greater burden for males. Females used humour and also appeared to make use of a wider support network (children, grandchildren, clinicians) to help them manage their condition, while males relied on their spouses. Travel to appointments and keeping track of multiple appointments was particularly burdensome for single patients (both males and females). Patients aged 60–79 were more likely to discuss being able to stay positive and appeared more likely to self-monitor, whereas older patients appeared to rely more on their clinicians and did little additional research to find out more about their conditions. Highly educated patients in particular flagged healthcare organisation issues such as fragmented care and poor communication and coordination between clinicians, but they appeared more able to express their needs with clinicians and were more involved in decisions regarding their care than patients with lower education levels. Highly educated patients as well as patients with greater CKD severity depended more on nephrologist for information and advice. In addition to appointment and travel burden, patients with greater CKD severity (CKD 4 or 5) were more likely to discuss complexity with medication such as drug interactions with other medications for other conditions as well as changing or conflicting information from clinicians than patients with CKD stage 3. Location of hospital was a challenge for rural patients and patients from lower socioeconomic background, though many rural patients were able to drive and some also able to choose their hospital. There were no appreciable differences in views of patients recruited from primary and secondary care.

There were differences in perspectives on the extent to which healthcare service and system-level factors influenced treatment burden. Patients attributed poor understanding of CKD and its treatment to poor provision of CKD information, whereas kidney care team members tended to focus on patients' health literacy levels. This finding is in line with the literature suggesting how, by whom and at what point self-care information is provided determine

how well patients may engage with and used the information.<sup>24</sup> Patients often expressed lack of choice and control over their management: (eg, having no choice but to take medication, wait for treatment, unexpectedly being taken off transplant list), suggesting suboptimal communication between patients and clinicians and lack of shared decision making. This highlights the importance of involving patients in their care and the need for good patient–clinician relationship and effective communication as well as consideration of what is truly best for the patient.<sup>25</sup> While clinicians need to acknowledge that patients' interest in engaging in decision making, patients also need to feel they have the knowledge, skills and confidence to make important health decisions.<sup>26</sup> Another difference was the extent to which treatment burden was perceived to impact on daily life—patients described being forced to withdraw from social activities, which was not noted by kidney care members. This withdrawal may result in isolation, particularly for those living alone. Some also chose not to burden family members with the management of their condition. These patients are a vulnerable group as social isolation has been associated with reduced self-efficacy to manage health.<sup>27</sup> Some of the discrepancies between patient and kidney care team perspectives may also have been due to the inclusion of healthcare professionals with a key role in CKD care, rather than broader healthcare specialists such as physiotherapists.

Our findings are consistent with the Cumulative Complexity Model which posits that the impact of treatment burden is dependent on each person's dynamic context, as well as the Burden of Treatment Theory which proposes that treatment burden influences the extent to which patients can engage in their healthcare and everyday responsibilities and relationships.<sup>7 8</sup> Our study findings are in line with a UK study among patients with CKD stage 4 exploring experiences of adopting recommended life style changes and showing that patients felt guilty about being a burden to others, difficulties with adherence and uncertainty over treatment plans.<sup>12</sup> One US study explored treatment burden in a low income, predominantly African-American community and identified four similar treatment burden themes to our study.<sup>28</sup> Previous international studies have identified variation in patients' understanding of CKD and a need for more CKD information and psychological support for people diagnosed with CKD and that acceptance, adopting a positive attitude and problem-solving were successful coping strategies that predialysis CKD patients adopted to successfully manage their health.<sup>10 29</sup> Similar themes have also been reported in other conditions.<sup>30–32</sup> However, life context and biography will shape how realistic coping strategies of positivity and problem solving are. The current study extends previous findings by bringing together patients' and healthcare professionals' views of treatment burden and capacity and highlighting important differences in perspectives of the two groups.

Strengths of the study were the inclusion of patients from a range of socioeconomic status, geographical

location and CKD severity stages. Furthermore, this study recruited via both primary care and secondary care, to capture perspectives of those less burdened and as much of CKD management occurs in primary care in the UK. The study also explored both treatment burden and capacity and views of both patients and a kidney team, allowing a more complete understanding. A limitation was the lack of input from primary care clinicians, as well as other specialties (eg, endocrinologists, cardiologists) with a key role in CKD care, which may have resulted in additional themes. However, previous studies exploring GP's views on the management of CKD in primary care have identified similar themes including barriers to understanding CKD and its treatment and anxiety over future consequences and medical factors.<sup>33–35</sup> Another limitation is participants being predominantly of white ethnicity meaning that it was not possible to examine the influence of ethnicity on treatment burden and capacity. The study was conducted in an area with predominantly white residents and the small proportion of non-white participants in our study is similar that of the area population. Finally, patients who agreed to participate might be more engaged or systematically different (eg, healthier, from less socioeconomically deprived areas) from those who declined to take part.

This study highlights the importance of the patient perspective, and the need for clinicians' understanding and availability to discuss the intersecting pressures, socioeconomic issues and comorbidities that patients experience. Careful assessment and improved documentation of individual patient capacity issues can help clinicians understand the extent to which patients can cope and develop more suitable treatment plans that meet patients' need.<sup>36</sup> Specific supporting services and better signposting (including sources of psychosocial support such as disease community, and sources of information on disability benefits, subsidised access to parking) can help improve the social care, psychological and financial needs that may make it difficult for patients to cope with their conditions. Better communication between healthcare professionals and patients allows opportunities for questions about CKD and enhances patient confidence.<sup>37 38</sup> While some treatment burden is inevitable, a degree may be lessened if comorbidities are adequately considered. Improved understanding and consideration of all the work patients need to do to follow treatment recommendations for each of their different conditions highlights the need for co-ordinated care among health specialists in order to reduce contradictory advice, fragmented care and unnecessary medication and appointments. Clinicians may need to adopt a pragmatic approach to care when developing management plans together with other health professionals.<sup>39</sup> The use of integrated systems can allow better communication between specialties (and between secondary, primary and social care). Both patients and healthcare professionals noted poor coordination of care. This may at least partly be because there is sometimes lack of clarity about who is the key coordinator

of care for people with CKD for example, GP or nephrologist. This is particularly true because patients seldom have CKD in isolation and often have other long-term conditions, so for some, for example, people with diabetes, they may even regard another hospital specialist as their main coordinator of care. In addition, with changes in primary care, there is often lack of continuity, that is, not seeing the same GP. The GP might previously have always been regarded as the central point of contact/care coordination for people. Therefore, clarity on the identity of the care coordinator may be needed to avoid confusion and ensure management plans are designed to take into account other long-term conditions.<sup>40</sup> Shared access to data and adequate facilities and training can also allow 'virtual' specialist consultation, which may be needed post-COVID-19 but also may reduce burden (while acknowledging the challenges of this for some patients).<sup>41</sup> There is some evidence to suggest virtual consultations may be associated with fewer unnecessary appointments, and increased engagement in care for patients with long term conditions.<sup>42</sup> Navigator programmes may also improve quality and process of care through addressing patient's individual needs and helping them overcome barriers to care. Evaluation of such programmes is underway, though studies have not focused specifically on a UK CKD population.<sup>43 44</sup>

## CONCLUSION

Improved understanding of and measures to reduce the treatment burden (eg, clear information, simplified (easy to follow guides explaining the medication and medication schedule) and appropriate medication, joined up care, free parking) associated with CKD in individuals as well as assessment of their capacity, better signposting to supporting services (disease community, financial benefits) and interventions to improve capacity (social care, psychological support) will likely improve patient experience and their engagement with kidney care services.

### Author affiliations

<sup>1</sup>Primary Care, Population Sciences and Medical Education, University of Southampton Faculty of Medicine, Southampton, UK

<sup>2</sup>Southampton Academy of Research, University Hospital Southampton NHS Foundation Trust, Southampton, UK

<sup>3</sup>Renal Medicine and Nephrology, University Hospital Southampton NHS Foundation Trust, Southampton, UK

<sup>4</sup>Renal Medicine, Royal Derby Hospital, Derby, UK

<sup>5</sup>Centre for Kidney Research and Innovation, University of Nottingham, Derby, UK

<sup>6</sup>Patient and Public Representative, Oxford, UK

<sup>7</sup>Department of Health Services Research and Policy, London School of Hygiene and Tropical Medicine Faculty of Epidemiology and Population Health, London, UK

**Contributors** Research idea and study design: SF, GL and PR; data acquisition: HH and SF; recruitment; HH, KV, KA and SF; data analysis/interpretation: HH, SF, GL, CM, MS, PR, MT, KV, KA and PA. Each author (HH, SF, GL, CM, MS, PR, MT, KV, KA and PA) contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

**Funding** The project was funded by The Kidney Patient Research Partnership Kidney Care UK & British Renal Society (BRS) Joint Grants Programme 2017 and was sponsored by the University of Southampton.

**Disclaimer** The study funder and sponsor did not have any role in the study design, data collection or analysis, writing of the final manuscript, or the decision to submit this manuscript for publication.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** The study was approved by the Health Research Authority and Health and Care Research Wales (HCRW reference:HRA245084) and London - Surrey Borders Research Ethics Committee (REC reference: 18/LO/1804).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as online supplemental information. All data relevant to the study are included in the article. No unpublished data are available outside of the study team.

**Supplemental material** This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

### ORCID iDs

Hilda O Hounkpatin <http://orcid.org/0000-0002-1360-1791>

Maarten W Taal <http://orcid.org/0000-0002-9065-212X>

Simon DS Fraser <http://orcid.org/0000-0002-4172-4406>

## REFERENCES

- Aitken GR, Roderick PJ, Fraser S, *et al*. Change in prevalence of chronic kidney disease in England over time: comparison of nationally representative cross-sectional surveys from 2003 to 2010. *BMJ Open* 2014;4:e005480.
- Hounkpatin HO, Harris S, Fraser SDS, *et al*. Prevalence of chronic kidney disease in adults in England: comparison of nationally representative cross-sectional surveys from 2003 to 2016. *BMJ Open* 2020;10:e038423.
- Tonelli M, Wiebe N, Guthrie B, *et al*. Comorbidity as a driver of adverse outcomes in people with chronic kidney disease. *Kidney Int* 2015;88:859-66.
- Fraser SDS, Roderick PJ, May CR, *et al*. The burden of comorbidity in people with chronic kidney disease stage 3: a cohort study. *BMC Nephrol* 2015;16:193.
- Nguyen HA, Anderson CAM, Miracle CM, *et al*. The association between depression, perceived health status, and quality of life among individuals with chronic kidney disease: an analysis of the National health and nutrition examination survey 2011-2012. *Nephron* 2017;136:127-35.
- Gallacher KI, Batty GD, McLean G, *et al*. Stroke, multimorbidity and polypharmacy in a nationally representative sample of 1,424,378 patients in Scotland: implications for treatment burden. *BMC Med* 2014;12:151.
- Shippee ND, Shah ND, May CR, *et al*. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *J Clin Epidemiol* 2012;65:1041-51.
- May CR, Eton DT, Boehmer K, *et al*. Rethinking the patient: using burden of treatment theory to understand the changing dynamics of illness. *BMC Health Serv Res* 2014;14:281.
- Demain S, Gonçalves A-C, Areia C, *et al*. Living with, managing and minimising treatment burden in long term conditions: a systematic review of qualitative research. *PLoS One* 2015;10:e0125457.

- 10 Teasdale EJ, Leydon G, Fraser S, *et al.* Patients' experiences after CKD diagnosis: a Meta-ethnographic study and systematic review. *Am J Kidney Dis* 2017;70:656–65.
- 11 . NICE Clinical Guidelines 182. *Chronic kidney disease: early identification and management of chronic kidney disease in adults in primary and secondary care*. London: National Institute of Health and Care Excellence, 2014.
- 12 Walker R, James H, Burns A. Adhering to behaviour change in older pre-dialysis populations—what do patients think? A qualitative study. *J Ren Care* 2012;38:34–42.
- 13 May CR, Cummings A, Myall M, *et al.* Experiences of long-term life-limiting conditions among patients and carers: what can we learn from a meta-review of systematic reviews of qualitative studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease? *BMJ Open* 2016;6:e011694.
- 14 Eton D, Elrayah TA, Yost K, *et al.* A systematic review of patient-reported measures of burden of treatment in three chronic diseases. *Patient Relat Outcome Meas* 2013;4:7–20.
- 15 Karamanidou C, Weinman J, Horne R. A qualitative study of treatment burden among haemodialysis recipients. *J Health Psychol* 2014;19:556–69.
- 16 Hallan SI, Matsushita K, Sang Y, *et al.* Age and association of kidney measures with mortality and end-stage renal disease. *JAMA* 2012;308:2349–60.
- 17 Roberti J, Cummings A, Myall M, *et al.* Work of being an adult patient with chronic kidney disease: a systematic review of qualitative studies. *BMJ Open* 2018;8:e023507.
- 18 Lemos CF, Rodrigues MP, Veiga JRP. Family income is associated with quality of life in patients with chronic kidney disease in the pre-dialysis phase: a cross sectional study. *Health Qual Life Outcomes* 2015;13:202.
- 19 Gerber LM, Barron Y, Mongoven J, *et al.* Activation among chronically ill older adults with complex medical needs: challenges to supporting effective self-management. *J Ambul Care Manage* 2011;34:292–303.
- 20 Johnson ML, Zimmerman L, Welch JL, *et al.* Patient activation with knowledge, self-management and confidence in chronic kidney disease. *J Ren Care* 2016;42:15–22.
- 21 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
- 22 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- 23 Ridgeway JL, Egginton JS, Tiedje K, *et al.* Factors that lessen the burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Prefer Adherence* 2014;8:339–51.
- 24 Protheroe J, Rogers A, Kennedy AP, *et al.* Promoting patient engagement with self-management support information: a qualitative meta-synthesis of processes influencing uptake. *Implement Sci* 2008;13:44.
- 25 Natalie J-W, Amy L, Adrian E, *et al.* Implementing shared decision making in the NHS: lessons from the magic programme. *BMJ* 2017;357:j1744.
- 26 Smith SG, Pandit A, Rush SR, *et al.* The role of patient activation in preferences for shared decision making: results from a national survey of U.S. adults. *J Health Commun* 2016;21:67–75.
- 27 Gallagher R, Donoghue J, Chenoweth L, *et al.* Self-Management in older patients with chronic illness. *Int J Nurs Pract* 2008;14:373–82.
- 28 Kahn LS, Vest BM, Madurai N, *et al.* Chronic kidney disease (CKD) treatment burden among low-income primary care patients. *Chronic Illn* 2015;11:171–83.
- 29 Subramanian L, Quinn M, Zhao J, *et al.* Coping with kidney disease – qualitative findings from the empowering patients on choices for renal replacement therapy (EPOCH-RRT) study. *BMC Nephrol* 2017;18:119.
- 30 Gallacher KI, May CR, Langhorne P, *et al.* A conceptual model of treatment burden and patient capacity in stroke. *BMC Fam Pract* 2018;19:9.
- 31 Kyle J, Skleparis D, Mair FS, *et al.* What helps and hinders the provision of healthcare that minimises treatment burden and maximises patient capacity? A qualitative study of stroke health professional perspectives. *BMJ Open* 2020;10:e034113.
- 32 Rosbach M, Andersen JS. Patient-experienced burden of treatment in patients with multimorbidity – a systematic review of qualitative data. *PLoS One* 2017;12:e0179916.
- 33 Tonkin-Crine S, Santer M, Leydon GM, *et al.* GPs' views on managing advanced chronic kidney disease in primary care: a qualitative study. *Br J Gen Pract* 2015;65:e469–77.
- 34 Blakeman T, Protheroe J, Chew-Graham C, *et al.* Understanding the management of early-stage chronic kidney disease in primary care: a qualitative study. *Br J Gen Pract* 2012;62:e233–42.
- 35 Herzig L, Zeller A, Pasquier J, *et al.* Factors associated with patients' and GPs' assessment of the burden of treatment in multimorbid patients: a cross-sectional study in primary care. *BMC Fam Pract* 2019;20:88.
- 36 Boehmer KR, Kyriacou M, Behnken E, *et al.* Patient capacity for self-care in the medical record of patients with chronic conditions: a mixed-methods retrospective study. *BMC Fam Pract* 2018;19:164.
- 37 Eton D, Ridgeway J, Linzer M, *et al.* Healthcare provider relational quality is associated with better self-management and less treatment burden in people with multiple chronic conditions. *Patient Prefer Adherence* 2017;11:1635–46.
- 38 Fraser S, Taal MW. Helping people to live well with chronic kidney disease. *BJHM* 2020.
- 39 Sav A, Kendall E, McMillan SS, *et al.* 'You say treatment, I say hard work': treatment burden among people with chronic illness and their carers in Australia. *Health Soc Care Community* 2013;35:n/a–74.
- 40 Major RW, Brown C, Shepherd D, *et al.* The Primary-Secondary care partnership to improve outcomes in chronic kidney disease (PSP-CKD) study: a cluster randomized trial in primary care. *JASN* 2019;30:1261–70.
- 41 Hull SA, Rajabzadeh V, Thomas N, *et al.* Do virtual renal clinics improve access to kidney care? A preliminary impact evaluation of a virtual clinic in East London. *BMC Nephrol* 2020;21.
- 42 Greenhalgh T, Vijayaraghavan S, Wherton J, *et al.* Virtual online consultations: advantages and limitations (vocal) study. *BMJ Open* 2016;6:e009388.
- 43 McBrien KA, Ivers N, Barnieh L, *et al.* Patient navigators for people with chronic disease: a systematic review. *PLoS One* 2018;13:e0191980.
- 44 Harvey C, Palmer J, Hegney D, *et al.* The evaluation of nurse navigators in chronic and complex care. *J Adv Nurs* 2019;75:1792–804.