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BMJ Open Patient and physician perspectives on treatment burden in end-stage kidney disease: a nominal group technique study

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ABSTRACT

Objectives The treatment workload associated with end-stage kidney disease (ESKD) is high. The treatment burdens experienced by patients with ESKD are not well understood. In this study, we aimed to elucidate the most important areas of treatment burden for discussion in a clinical encounter from the perspectives of patients with ESKD and nephrologists. We sought to explore possible solutions to these high priority treatment burden challenges.

Design Nominal group technique (NGT) sessions.

Setting and participants Three in-person NGT sessions were conducted with 19 patients with dialysis-dependent ESKD from one tertiary treatment centre (mean age 64 years; range 47–82). All patients were either retired or on a disability pension; 74% perceived moderate or severe treatment burden; and 90% spent more than 11 hours on treatment-related activities per week (range 11–30). One online NGT session was conducted with six nephrologists from two Australian states.

Main outcome measures The primary outcome was a ranked list of treatment burden priorities. The secondary outcome was potential solutions to these treatment burden challenges.

Results Every patient group ranked *health system issues* as the most important treatment burden priority. This encompassed lack of continuity and coordination of care, dissatisfaction with frequent healthcare encounters and challenges around healthcare access. *Psychosocial burdens* on patients and families were perceived to be the most important area of treatment burden by physicians, and were ranked the second highest priority by patients.

Conclusions Discussing treatment burden in a clinical encounter may lead to a better understanding of patients' capacity to cope with their treatment workload. This could facilitate tailored care, improve health outcomes, treatment sustainability and patients' overall quality of life.

INTRODUCTION

Chronic kidney disease (CKD) is associated with significant morbidity and mortality with an estimated global prevalence of 698 million cases in 2017, disproportionately affecting socioeconomically disadvantaged populations.¹ Early recognition and interventions to address modifiable risk factors are priorities in preventing CKD and its progression

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study identified treatment burden priorities for discussion in a clinical encounter from patients with end-stage kidney disease (ESKD) and nephrologists' perspectives.
- ⇒ The nominal group technique consensus approach allowed multiple treatment burden issues to be generated and prioritised with balanced participant involvement.
- ⇒ A small number of patients with ESKD were recruited from one Australian tertiary hospital limiting the study's generalisability.

to end-stage kidney disease (ESKD) where renal damage is irreversible.^{2–3} As CKD progresses to stages IV and V (defined by an estimated glomerular filtration rate ≤ 30 mL/min/1.73 m² and ≤ 15 mL/min/1.73 m², respectively), symptom burden progressively increases with patients reporting fatigue, weakness, sleep disturbances, itch, nausea, anorexia, bone pain, muscle cramps and restless legs.^{4,5} High symptom burden contributes to frailty, declining functional status and poor health-related quality of life.^{6,7}

CKD management is multifaceted and complex even before these often elderly, multimorbid patients reach ESKD.⁸ Patients' treatment workloads go beyond time spent on dialysis circuits, with many unseen hours, efforts and manpower utilised to maintain their health, prevent and recognise any deterioration.⁹ As CKD advances, the treatment regimen becomes increasingly onerous with hospitalisations, frequent clinical appointments, investigations, procedures and increased medications.^{10,11} Each of these tasks add to patients' cognitive loads and carry adverse financial, psychological and social consequences for patients and their families.¹² The treatment workload in those receiving dialysis or transplant is even more burdensome.¹⁰ Elderly patients are increasingly initiated on dialysis, but evidence suggests that



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they often struggle with CKD self-management, and a conservative approach focused on improving quality of life should be favoured.¹³

Although it is understood that *symptom* burden impacts patient well-being, there is less awareness of the impact of prescribed *treatments* on patients. When care needs exceed the patient's and their support system's capacity to engage in their chronic disease management, there is increased risk of treatment failure and poor patient outcomes.¹⁴ Patients with CKD, especially those on dialysis, have a significant treatment workload, which impacts all facets of their life. This is embodied in the term 'treatment burden', an emerging concept in the healthcare field, especially in chronic disease care.^{15 16} To date, qualitative studies mostly explored the patients' and physicians' perspective of treatment burden in a heterogeneous chronic disease population.^{17 18} Few studies have explored patient perspectives of treatment burden in the adult ESKD population.^{10 12 19–22} There are, however, no studies which have delineated treatment burden priorities from patient with adult ESKD and physician perspectives.

Overall, positive treatment outcomes depend on the ability of patients, their families and the health system to withstand the stresses and demands of their treatment workload. Exploring this aspect of the patient experience during patient–physician encounters is paramount for better tailoring care.^{23 24} Therefore, we aimed to identify areas of treatment burden that patients with CKD on dialysis and nephrologists wish to discuss in the clinical encounter, and to explore possible solutions.

METHODS

We conducted four NGT sessions in 2021, three with patients with ESKD and one with nephrologists. The patient sessions were conducted face-to-face at Gold Coast University Hospital and Health Service (GCHHS). The physician session was conducted via an online video teleconferencing platform. We aimed for five to nine participants per group.²⁵

Participant recruitment

Patients

Prospective participants aged over 18 diagnosed with CKD stage V (ESKD) were purposively sampled from the ESKD register at the GCHHS by the study coordinator. Participants were recommended for the study by treating nephrologists, dialysis nurses, nurse-unit managers and nurse practitioners. Interest for the study was first discussed with prospective participants during a clinic visit or phone review by a GCHHS clinician. Potential participants were then approached in-person or via phone call by the study coordinator to discuss the study in detail and collect participant data. Attempts were made to recruit patients with diverse characteristics: age, gender, marital status, employment, home or hospital dialysis, dialysis modality (ie, haemodialysis or peritoneal dialysis), comorbidities and medication burden. Participant

information sheets were sent to interested participants and signed consent was obtained prior to study participation (online supplemental appendix 1: Patient Information Sheet and Consent Form).

Physicians

Nephrologists from the Australian States of Queensland and New South Wales were identified by the senior investigator (CCD). Potentially eligible physicians were approached via email by the study coordinator with a participant information and consent form. Signed consent was obtained prior to study participation.

Study design and procedure

We used nominal group technique (NGT), a mixed methods consensus approach to generate and prioritise treatment burden topics. This method was chosen for several perceived advantages over general focus groups.^{26–30} This consensus method allows individuals to efficiently generate multiple ideas in response to the research question. These ideas are then shared and discussed, which offers the opportunity for snowballing of ideas and generating new discussion points. Through a process of voting and ranking, individuals can reflect on and prioritise issues from their perspective. NGT encourages active participation of every group member rather than having discussions dominated by an outspoken few. The NGT procedural steps are outlined in [table 1](#). Two or three study investigators and the study coordinator were present at each NGT session with specific roles (facilitator, scribe, process coordinator, and/or observer) (see online supplemental file 1: Participant worksheet and discussion guide).

To mitigate possible researcher bias when documenting discussion points during the NGT sessions, two researchers transcribed and cross-checked data. A third researcher was present to oversee discussions and give a consensus opinion if there were any disagreements. Transcriptions were projected live on a projector for session participants to view and correct if they felt misquoted.

Data processing and analysis

Results from different patient groups were aggregated, and the results from the physician group were analysed separately.³¹ For generating the treatment burden themes:

1. Two researchers grouped similar treatment burden topics from the patient participant groups under umbrella themes (online supplemental appendix 2: Treatment burden topics and themes).
2. Scores of all issues under the same umbrella theme were aggregated.
3. Treatment burden themes were ranked in order of highest importance according to their aggregate scores from the three patient groups. If scores for two or more umbrella themes were equal, the theme which was more frequently identified as one of the top five perceived treatment burdens by participants across the three NGT sessions ranked higher.

Table 1 Nominal group technique process steps

Introduction	A brief introduction to the research aims and objectives were provided. Patient and physician participants were asked to reflect on: What issues related to the patients' burden of treatment do you think should be discussed between doctor and patient?
Silent reflection and idea generation	Participants were asked to silently pen their responses to the focus question.
Round robin	Participants consecutively presented one response at a time to the focus question until no new ideas were generated. ³³ These ideas were transcribed on an excel spreadsheet projected live, providing participants with the opportunity to give feedback.
Discussion	Participants elaborated on issues they raised in the round robin and clarified any ambiguity. New ideas were also generated.
Participant break and concurrent investigator discussions.	Any overlapping ideas were then grouped and summarised by investigators.
Clarification	The updated list of summarised ideas was shown to participants. Feedback was sought, and clarifications made to ensure agreement on the final list of perceived treatment burden issues.
Voting and ranking of treatment burden themes	Participants selected and ranked the top five perceived treatment burdens individually in order of their perceived importance using a 5-point scale (5=most important/relevant and 1=least important). The individual scores were aggregated and the top five treatment burden issues presented.
Solutions	Participants were encouraged to discuss potential solutions to the top five ranked treatment burden issues. These solutions were documented in a separate excel spreadsheet. This component of the session was audio-recorded and transcribed for qualitative analysis.

4. Data were cross-checked and agreed on by consensus discussion with all investigators to ensure that the final themes were robust and accurately reflected the information obtained from participants. This was to minimise loss of nuances in the original data, particularly if discussion points slightly overlapped into another umbrella theme.

Patient and public involvement

Patients or members of the public were not involved in this study's conceptualisation. Our study's research question and outcome measures were informed by the experiences of patients who experience chronic diseases and existing literature indicating a need for patient-centred research. The study's findings will be disseminated to patient participants, clinicians, the hospital's research and governance committee, and the wider community through publication in an open-access journal.

RESULTS

Nineteen patients with CKD participated in three in-person NGT sessions conducted between February and June 2021. Baseline patient participant characteristics are depicted in [table 2](#). The mean age of patient participants was 64 years (range 47–82). There was approximately even gender representation (53% male and 47% female). None of the patient participants were employed. Seventy-four per cent perceived their treatment workload as moderately or severely burdensome. Eighty-four per cent took more than six pills per day (range 6–20), and 90% spent 11 or more hours on treatment-related activities per week (range 11–30).

Six physicians participated in an online NGT session conducted in September 2021. Five were nephrologists, and one participant was a specialist trainee. Four physician participants (67%) were men.

Seven themes arose from the treatment burden topics generated in the three patient NGT sessions ([table 3](#)) and six themes in the physician group ([table 4](#)). Five themes overlapped: (1) behavioural and lifestyle changes, (2) financial burden, (3) health system issues, (4) medication issues and (5) psychosocial burden on patient and family. Two themes were exclusively raised by the patient group: (1) patient and family communication, information and education and (2) experience with ancillary services. One theme (transplantation journey) was raised only in the physician group. [Figure 1](#) compares the patients' and physicians' perceived treatment burden priorities. The top five treatment burden themes identified by patients and physicians will be discussed.

Theme 1: health system issues

This theme was ranked the most significant area of treatment burden across all three patient CKD groups. This was the second most important treatment burden theme according to the physician NGT group. Health system issues encompassed:

- ▶ Continuity and coordination of care (within and across healthcare disciplines and sectors, ie, medical, allied health and administrative areas);
- ▶ Healthcare encounters (frequency of healthcare encounters, including specialist and allied health appointments, investigations and treatments); and

Table 2 Patient with end-stage kidney disease participant characteristics

Characteristics	N (%) n=19
Sex	
Male	10 (53)
Female	19 (47)
Age (years)	
Mean: 64	
Range: 47–82	
40–49	2 (11)
50–59	3 (16)
60–69	8 (42)
70–79	5 (26)
80–89	1 (5)
Marital status	
Single	2 (11)
De-facto	1 (5)
Married	10 (53)
Separated; divorced	6 (32)
Country of birth	
Australia	11 (58)
New Zealand	3 (16)
East Asia	1 (5)
Pacific Island Nations	1 (5)
European countries	3 (16)
Employment	
Aged pension (retired)	12 (63)
Disability pension	7 (37)
Dialysis modality and delivery	
APD	3 (16)
Centre HD, failing PD	9 (47)
Centre HD only	3 (16)
Home HD	4 (21)
Transplantation	
Previous allograft (failed)	1 (5)
Undergoing transplant evaluation	6 (32)
Years since commencing dialysis	
Median: 3	
Range: 0–11	
0–2	9 (47)
3–5	5 (26)
6–8	3 (16)
9–11	2 (11)
Comorbidities	
Hypertension	18 (95)
Diabetes	7 (37)
Asthma/COPD/OSA	4 (21)

Continued

Table 2 Continued

Characteristics	N (%) n=19
Ischaemic heart disease/heart failure	7 (37)
Peripheral vascular disease	4 (21)
Stroke	4 (21)
Osteoarthritis/gout	6 (32)
Active cancer (oesophageal, prostate)	2 (11)
Other neurological conditions (seizures, restless legs, tremor)	3 (16)
Perceived degree of burden*	
Minimal (1+)	5 (26)
Moderate (2+)	7 (37)
Significant (3+)	7 (37)
Daily number of pills	
0–5	3 (16)
6–10	9 (47)
11–15	6 (32)
16–20	1 (5)
Time spent on management (hours per week)	
≤10	0 (0)
11–20	13 (69)
21–30	3 (11)
>30	1 (5)
Missing	1 (5)

*Perceived degree of burden is the self-reported level of treatment burden experienced by patient participants, expressed using the following scale; not at all burdened (0), somewhat burdened (1), significantly burdened (2), overwhelmingly burdened (3). APD, ambulatory peritoneal dialysis; COPD, chronic obstructive pulmonary disease; HD, haemodialysis; OSA, obstructive sleep apnoea.

- Healthcare access (accessing treatment or specialist appointments).

Continuity and coordination of care

Medical

ESKD patients across all three NGT groups experienced inconsistencies in care and communication within and across medical disciplines. At the primary care level, patients perceived that communication and coordination of care between their general practitioner and specialist was lacking. Patients mentioned there was a 'long way to go to make sure [communication] was streamlined effectively', particularly after specialist appointments and hospitalisations. Physicians agreed that 'care gets fragmented with patients being seen by clinicians in different places and [delays in] communication or letters from specialists and other professionals'. Frequent monitoring and changes to their treatment made by their renal specialist seemingly limited the role that primary care doctors played in their care. Some patients felt that because 'non-renal clinicians lack specialist knowledge

Table 3 Patients with end-stage kidney disease's treatment burden themes and priorities (n=3 groups, 19 participants)

Umbrella themes	Group 1 scores (ranking) n=8	Group 2 scores (ranking) n=6	Group 3 scores (ranking) n=5	Aggregate scores for theme	Frequency of votes for theme	Ranking
Health system issues	36 (#1)	38 (#1)	37 (#1)	111	35	1
Psychosocial burden on patient and family	18 (#3)	20 (#2)	20 (#2)	58	18	2
Patient and family communication, information and education	31 (#2)	2 (#=5)	8 (#4)	41	15	3
Behavioural and lifestyle changes	10 (#5)	16 (#3)		26	8	4
Financial burden	11 (#4)	2 (#=5)	10 (#3)	23	9	5
Medication issues	9	9 (#4)		18	6	
Experience with ancillary services	5			5	2	

of renal patients' issues, [patients] have to advocate for [themselves]'. They reported having to be vigilant and discerning with advice from junior or non-renal clinicians who are only transiently involved in their care, have varying knowledge of their condition and differing perspectives. This became even more burdensome when patients were unwell in the emergency department.

Allied health

Many patients felt they needed a dedicated nursing and allied health team, who understood the complexities of being a dialysis patient, and 'early identification and timely support from allied health (eg, social workers, dietetics) was vital to sustaining treatment'. Home dialysis patients felt issues like ensuring accommodation was suitable for setting up a haemodialysis or peritoneal dialysis machine (eg, plumbing or storage space for equipment) should be anticipated and addressed earlier. They perceived that 'communication across allied health disciplines and treatment centres was deficient' and late recognition of preventable issues precipitated social crises and hospitalisations. Physicians, however, only discussed the possible inconvenience of attending many allied health appointments.

Administration

Concerns with care coordination also encompassed administrative problems like appointments with different specialties or tests not being streamlined, difficulties changing or confirming appointment times with long wait-times on the phone and no obvious contact person

to liaise with to coordinate appointments. In one patient's experience, 'I sat on the phone for three-quarters-of-an-hour to respond to whether I'm coming to that appointment, whereas all other facilities just ask me text back yes or no, Y or N'. Another patient reported, 'I had an appointment a couple of weeks ago. One was an echocardiogram and one was a stress test in the same department. I had to wait an hour-and-a-half between appointments and I had to pay the extra parking costs'. There were no physician comments pertaining to how hospital administrative processes impacted on patients' treatment burdens.

Healthcare encounters

Frequent appointments with specialists or allied health staff, providing blood tests or specimens, and getting imaging or procedures were taxing on patients. Physicians also appreciated that the 'frequency of diagnostic and complication monitoring with investigations and appointments' was demanding. This was compounded by the need to come to hospital for dialysis. As one patient explained: healthcare encounters 'take time away from more important activities'. Many agreed that their daily routines ended up revolving around 'multiple appointments with different specialists at different centres' which included a lot of waiting time. This problem was aggravated when their condition and treatment required more intensive monitoring for 'persistent problems like elevated potassium and blood pressure issues'. Additionally, hospitalisations were disruptive for patients and families.

Table 4 Physicians' perspective on patients with end-stage kidney disease's treatment burden—themes and priorities (n=1 group, 6 participants)

Umbrella themes	Aggregate scores for theme	Frequency of votes for theme	Ranking
Psychosocial burden on patient and family	30	9	1
Health system issues	21	10	2
Financial burden	16	4	3
Behavioural and lifestyle changes	13	4	4
Medication issues	10	3	5
Transplantation journey	0	0	

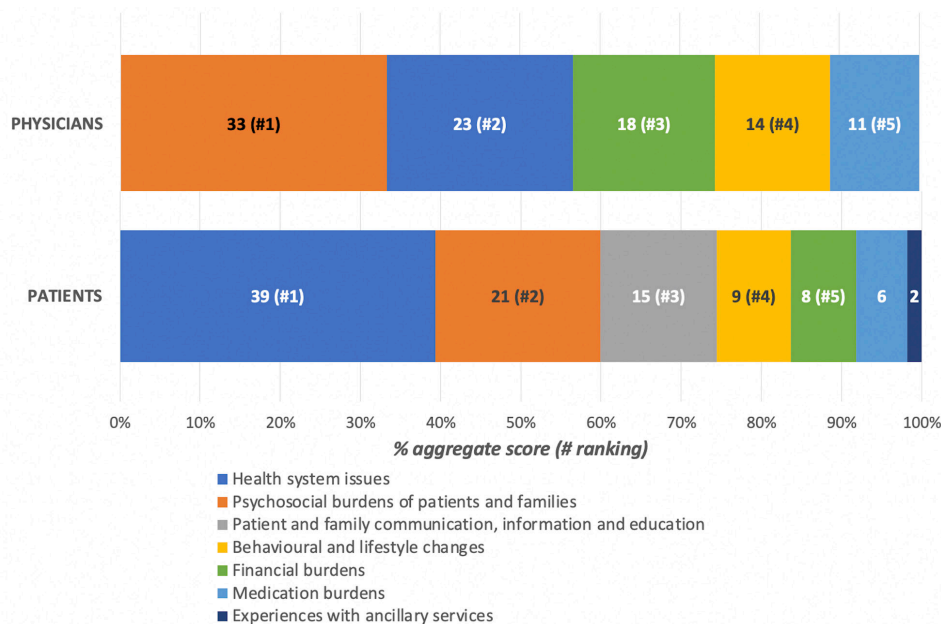


Figure 1 Comparison of treatment burden priorities in patients and physicians. Aggregate scores; patients=282 points, physicians=69 points.

Healthcare access

Patients reported problems with accessing treatment and their specialists. They specifically mentioned the lack of flexibility in location and timing of appointments and dialysis, in addition to parking fees. Many had to plan their life around these healthcare encounters and even relocate closer to a treatment centre to reduce travel times. One patient mentioned that because of parking, 'my husband used to drop me and then I went into the appointment on my own, which then negates the fact that he's my carer, because he's missing out on the vital information. That's why we moved closer because we thought then we could overcome that'. Physicians mentioned that in their experience, some patients with ESKD felt the 'burden of transport to and from the facility, if they could not drive to appointments due to driving restrictions'.

Theme 2: psychosocial burden on patients and families

Physicians thought that psychosocial burden was the most important treatment burden priority patients wanted to discuss in a clinical encounter. In their experience, physicians saw how their patients 'grieved the loss of freedoms', opportunities and ability to make plans for a multitude of reasons not limited to 'fatigue, frequency of dialysis and the highly structured and intense nature of [their] treatment regimen'. Physicians also perceived that while patients and families adjusted to the stresses of treatment, there were adverse ramifications on relationships. 'Families who were not so aware of the nature of their illness get frustrated when [their loved one] was not able to participate in social and family events' leading to isolation. Patients reported guilt, frustration, depression and anxiety when they saw their state of health affect the social, emotional and financial well-being of their family and carers. To cope with the challenges of treatment,

patients recognised that they must adjust by making permanent life changes like stopping employment, study or moving closer to hospital with significant help and support from others. Evidently, none of the included patient participants could hold down part-time or full-time employment due to disease and treatment burden.

Theme 3: patient and family communication, information and education

This was the third most important theme raised by the patient cohort and a popular discussion point across the three NGT patient groups. This theme did not appear in the physician NGT group discussion. The theme encompassed issues with:

- ▶ Communication
- ▶ Information provision and education

Communication

Patients explained that they sought qualities of honesty and empathy in their doctor and did not want 'sugar-coating' of information. Some expressed that they would like family and significant others to be involved in important discussions for support because they could add valuable insights into their life and preferences.

Information provision and education

Patients often expressed the need for more discussion around treatment options (including renal transplant), treatment side effects and the significance of any test results. They also wanted better information on signs and symptoms that should trigger a visit to the emergency department. Patients were concerned that significant others and carers needed to be adequately educated on the patients' condition and treatment because some families were suddenly confronted with having to make life

adjustments, causing confusion, turmoil and distress in caregivers. As one patient put it, they ‘just needed a bit more support and information in what they can do’.

Theme 4: behavioural and lifestyle changes

This theme was the fourth most important area of treatment burden identified by both patients with ESKD and physicians.

Behavioural changes

Patients were affected negatively by dietary restrictions. This included closely monitoring fluid, sodium, potassium, phosphate intake as part of CKD management. The restrictions further compounded when CKD coexisted with other common comorbidities like diabetes. Confusion around what constitutes a renal diet was common among patients as it was specific for each patient. In one patient’s experience, ‘when I come into the hospital here, they’ll put me on to a renal diet but there’s no fresh fruit in it and they’ll give me apple juice, or they’ll give me orange juice which is high in citric acid which we’re not supposed to have in our diets. Everything is also high in salt.’

Lifestyle

Renal replacement therapies were reported to adversely affect patients’ lifestyle, and invariably their sleep, and the ability to socialise and travel. One peritoneal dialysis patient reported difficulties sleeping as they felt ‘the machine at night draining and then filling [the abdomen with dialysate which] wakes me up for every one-and-a-half-hour cycle’. Many struggled with ‘the lack of sleep or getting solid uninterrupted sleep... it could be the medication. It could be having hot flashes during the night which I think we’ve all experienced’. The ability to socialise was also limited with another patient stating, ‘I live two doors away from another guy on dialysis. The only time I see them is when we leave dialysis. I don’t see them at all...you’re either tired or you don’t interact’.

Theme 5: financial burden

Patients reported this as the fifth most significant area of treatment burden they wish to discuss with their physician. Physicians ranked this issue third. Physicians believed that loss of employment for patients and carers meant most were living on a disability or government pension. Costs of medication were significant with 84% of ‘the patients reporting they took six or more pills daily which does not include infusions and injections. Home haemodialysis patients had additional costs for medications (such as iron infusions) that were subsidised for in-centre dialysis patients. Other unseen expenses included petrol and parking fees, public transport fees when going for appointments or treatment. For home dialysis patients, there were costs associated with running the dialysis machine including electricity, water bills and costs of dialysate treatment bags.

Theme 6: medication issues

Medication issues were deemed the fifth most important treatment burden topic for discussion in the clinical encounter by physicians, who recognised that the treatment regimens were complex and dynamic as the condition changed, especially when ‘multiple specialists are involved in their care and making medication changes’. This posed a significant cognitive load for patients and carers, especially ageing patients. Challenges around medication became even more demanding around the time of transplant. Patients, however, did not rank this in their top five priorities. They mainly reflected on the need to visit doctors for filling in scripts and they found medication changes and substitutions without explanation or consideration of its cost by the treating physician problematic.

Brief overview of themes which did not rank in the top five priorities

- ▶ *Experience with ancillary services.* One patient raised their dissatisfaction with food services and the room temperatures.
- ▶ *Transplantation journey.* The physician group mentioned that preventative measures related to transplantation such as changing lifestyle, preventing infection, bone protection, malignancy screening, managing cardiovascular risk factors, new dietary restrictions and medications could be burdensome.

Proposed solutions to treatment burden issues

Table 5 gives an overview of possible solutions suggested by patient and physician participants to the different treatment burden challenges outlined above.

DISCUSSION

Summary of principal findings in context of existing literature

The study offered new insights into areas of treatment burden which patients with ESKD and nephrologists felt should be prioritised for discussion in a clinical encounter. In general, the issues raised were broadly similar with some differences in the ranking of priorities between patient and physician groups. Patients felt most of their treatment burden arose from *health system issues*, and they desired better communication and coordination across medical disciplines, allied health as well as administration within the hospital system and externally with other care providers. Physicians appreciated that patients did not want to frequent the hospital so often for appointments and investigations. Overall, patients with ESKD with high symptom and treatment burden found the health-care system challenging to navigate and this was a major source of frustration and fatigue. Patients and physicians derived feasible solutions which require working with health service management to streamline care.

Physicians and patients also agreed that the psychosocial burden of treatment was an important area which is consistent with the qualitative CKD literature.¹⁹ There is a shift

**Table 5** Proposed solutions to treatment burden issues by patient and physician participants

Umbrella themes	Proposed solutions
Health system issues	<ul style="list-style-type: none"> ▶ Streamline services for renal patients with high care needs. ▶ Avoiding clinical overbooking. ▶ Better coordination of appointment scheduling. ▶ Automated strategies for appointment scheduling; more direct communication channels to enquire about or change appointments. ▶ Better coordination of communication between medical specialties and family physicians (or general practitioners). ▶ Centralised communication systems between family physicians (or general practitioners) and other care providers with electronic notification of treatment plan changes and follow-up needs. ▶ Combining appointments or having them in a multidisciplinary format so that it is a 'one-stop-shop' to minimise time needed to come to dialysis, pharmacists and other specialists. ▶ Specific contact details given on a card to avoid long phone queues. ▶ Opportunistic clinician visits, phone reviews, telehealth appointments during dialysis sessions.
Psychosocial burden on patient and family	<ul style="list-style-type: none"> ▶ Carers and support workers to be included in the consultation. ▶ More information and education for (formal and informal) caregivers. ▶ Doctors to facilitate or streamline contact with a social worker or counsellor. ▶ Have a core group of multidisciplinary staff who understand the issues specific to their condition. ▶ Membership in a renal support group to interact with similar patients and nurses as a group where there are face-to-face and online discussions to share resources and ideas. ▶ Culturally appropriate support to fill forms, eg, National Disability Insurance Scheme applications.
Patient and family communication, information and education	<ul style="list-style-type: none"> ▶ Honest, empathic communication from doctors. ▶ Renal educators (not necessarily a doctor) to provide information early about the nature of the treatment. ▶ Emails from the chronic kidney disease team with important updates. ▶ Information evenings. ▶ Information sheets around the condition and what to expect at the time of diagnosis.
Behavioural and lifestyle changes	<ul style="list-style-type: none"> ▶ Strong dietitian service for education and follow-up to support the burden of dietary modifications; rather than brief clinician-led discussions. Individual dietary assessments tailored to needs and shifting the focus to individualised substitutions and changes. ▶ Not blaming patients or making them feel guilty; being pragmatic when they falter.
Financial burden	<ul style="list-style-type: none"> ▶ Doctors to better understand the cost of what they prescribe and suggest alternatives. ▶ Support with parking on the pension.
Medication issues	<ul style="list-style-type: none"> ▶ Deprescribing and reducing polypharmacy. ▶ Other staff to be able to issue scripts. ▶ A registry with ready access to a current list of patient medication.

towards patient-centred research, and the Standardised Outcomes in Nephrology-CKD initiative highlighted in their work that research should focus on patient-centric outcomes.²⁰ Patients in their study discussed how depression, dialysis-free time, impact on family and friends were important outcome measures and indicators of psychosocial burden which should be included in research. Similar psychosocial issues were popular discussion points in our study's patient with ESKD group.

Patients in our study highlighted the need for empathic and honest communication, information and education, which was not raised in the physician group. It may be that physicians already felt they spend a lot of time providing information and education within consultations, and that the department had invested in patient education resources. A recent UK qualitative study found that patients were not given adequate information on how to manage the condition, and the kidney care team perceived this to be related to health literacy.¹⁰ Indeed, health literacy may be a factor in their ability to retain

information, but patients' fatigue, cognition dysfunction associated with CKD, ageing and the complex health-related tasks for self-management cannot be overlooked. Many patients and families are also overwhelmed emotionally as they grapple with prognosis and undertake future planning. Patients in our study stated they needed their physicians to be patient, understanding and reiterate information at different times, through different people and formats. Formal and informal support groups and information evenings could be a way of normalising patients' experiences and developing alternate support systems. Though there are local and national CKD support groups, many patients in our NGT groups were not aware of their existence suggesting more needs to be done to actively promote them.

The behavioural and lifestyle changes required in CKD treatment were also highlighted as an area of treatment burden. This corroborates with existing literature stating that dietary changes and fluid restrictions significantly impact the lives of patients with CKD and caregivers. A

systematic review of qualitative studies identified that patients' attitudes around dietary changes depended on its impact on relationships, their experience with navigating change, difficulties fighting temptation, need to optimise health and empowerment.²¹ The review reported that patients found dietary and fluid restrictions disorienting and intense. Patients wanted education, collaboration and strategies to stay motivated to optimise their health with the least restriction on quality of life. Further, patients in our study wanted pragmatic advice and close collaboration with dietitians on dietary recommendations to maximise long-term adherence.

Physicians mentioned medications as an important treatment burden area. Patients' medication-related concerns focused on pill burden and inconvenience of getting prescriptions with lack of streamlined processes. Somewhat surprisingly, patients did not mention dialysis as a significant source of treatment burden despite it being such a large part of their treatment workload. This is consistent with other ESKD treatment burden studies.^{10 12} It may be that patients are more willing to accept dialysis-related treatment burdens as they perceive it to be life-saving.

While transplantation was raised as a possible treatment burden priority, patients and physicians did not rank this in the top five priorities. It is possible that patients were satisfied with existing patient education processes, locally and at the transplant centre. However, from a physicians' perspective, pre-transplant investigation updates (eg, annual echocardiogram, antibody and virologic screening) may be a burden when assessing suitability for transplant. Additionally, there were concerns that patients may not be fully cognisant of the nuances of post-transplant care including monitoring for rejection, drug levels and interactions, preventing opportunistic infections and cancer screening.

Our study findings generally concur with the literature, however there are some notable differences. A systematic review of qualitative studies in the CKD population included 260 studies from 30 countries with 5115 patients and 1071 carers.²² Similar themes to our study did emerge such as difficulties with self-care, navigating healthcare systems, managing information and burden on social supports. Unlike our study however, the review mainly emphasised the impact of patients' socioeconomic status (income level, insurance status and locality) on their ability to pay and access healthcare including dialysis. Financial burden was of critical concern for patients with CKD particularly in countries without a universal healthcare system. In contrast, patients with ESKD in our study rated financial burdens as their fifth priority as the universal healthcare system in Australia generally delivers affordable and equitable healthcare.³² Of note, the included studies in the systematic review had variable quality of reporting, heterogeneity in the research question and study methodologies.²²

Strengths and limitations

This study offers novel insights into the most burdensome aspects of the patients with adult ESKD's high treatment workload and an insight into physician's awareness of those burdens. A strength of this study was that the patients with ESKD's perspectives and priorities were independently identified and then compared with specialist physicians, mostly from the same treatment centre. Using NGT ensured the preferences and perspectives of individual participants were valued equally. Unlike other studies, our methodology allowed participants to prioritise areas of treatment burden. This study also offered patients the opportunity to present their own solutions to the treatment burden topics raised. Prioritisation of treatment burden themes as well as focus on solutions should give policymakers and hospital management impetus and strategies for improving their model of care.

The data generated in this study reflected the experience of patients in one centre and there may be unique or dissimilar treatment burden priorities experienced by patients with a different demographic profile or in other treatment centres. The study may have had selection bias for medically stable and vocal study participants. It is probable that GCHHS staff were more inclined to recommend patients for the study if they could articulate themselves well and had the willingness to participate. Conversely, those with (1) cognitive impairment, (2) speech and language difficulties (eg, non-English speaking background, patients who had stroke), (3) significant medical and treatment burdens (eg, hospital in-patients, palliative care patients) and (4) difficult social situations were less likely to be represented in this volunteer participant population. Younger patients were under-represented; however, this was not surprising as patients with ESKD under 60 years of age are more likely to have undergone renal transplants. Overall, however, our findings were generally aligned with previous results of studies that evaluated treatment burden in patients with CKD.

CONCLUSION

Frequency of healthcare encounters, healthcare access and inadequate coordination and continuity of care at a medical, allied health, administrative levels were significant sources of treatment burden. While solutions to some of the challenges might arise in the clinical encounter between patient and physician, other challenges need to be addressed at a health system level. Early identification of psychosocial issues and closer, integrated involvement of social workers and counsellors may prevent unwanted hospitalisations and minimise patient distress. Discussing treatment burdens and exploring solutions in clinical encounters are likely to increase patients' capacity to cope with the high treatment demands. This might translate to improved health outcomes, efficiency in healthcare, and most importantly, patients' overall quality of life.

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Contributors STT contributed to study protocol, ethics approval, nominal group technique session facilitation, data acquisition, analysis and interpretation and initial drafting of the manuscript. MC and AS contributed to study protocol and design, data acquisition and revision of manuscript for important intellectual content. RT (co-investigator) facilitated sessions, drafting and revisions of the manuscript. ZM facilitated sessions and reviewed the manuscript. TTT assisted with study site approval, participant recruitment and provided content expertise in revision of the manuscript. CCD (lead investigator and supervisor) conceived and designed the study protocol, obtained grant and ethics approval for the study, contributed to physician recruitment, data acquisition, analysis and interpretation, initial and critical revision of manuscripts for important intellectual content. All authors have read and approved the final manuscript. STT (guarantor) accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

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Author note STT is an emerging researcher and medical doctor with clinical experience in chronic disease care. CCD is a respiratory physician with clinical and research expertise in treatment burden having published extensively on patients with chronic respiratory diseases. AS is a social scientist and senior lecturer who has published widely on the use of nominal group technique and treatment burden. RT is a psychologist with extensive research experience including group facilitation and qualitative analyses. MC is a medical doctor with qualitative research experience, particularly in palliative care medicine and end-of-life decision-making. ZM is a physiotherapist and researcher with experience in patient-centred research in musculoskeletal diseases. TTT is a nephrologist with expertise in chronic kidney disease, dialysis and transplant medicine.

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RESEARCH PARTICIPANT INFORMATION STATEMENT

Research Study Title	Developing a tool on treatment burden for the patient-physician encounter: Towards a patient-centred approach in chronic disease care
Principal investigator Phone Contact	Associate Professor Claudia Dobler 02 8738 3000

(1) What is the study about?

You are invited to participate in a research project because you have been identified as a patient or carer living with a chronic health condition or you are a doctor treating patients with chronic health conditions.

Treatment burden is the work patients living with a chronic health condition and carers undertake to manage their health and the impact of this treatment on their lives. Treatment workload includes taking medication, attending medical appointments, bloods tests, monitoring health, diet, exercise and other activities.

Our research team is hoping to learn from your health experiences. You were hand-picked by the team as a potential participant in this study because we believe your insights and contributions would be valuable in understanding more about patient, carer or physician experiences of living with and/or managing a chronic health condition. The results of these discussions will go on to help us develop a tool which we can use to prompt discussions with other patients and carers about burden of treatment. Together, we hope patients and physicians can find a treatment plan which is tailored, effective, and sustainable and improves the lives of patients and carers.

(2) Who is carrying out the study?

The coordinating principal investigator Associate Professor Claudia Dobler works as a consultant respiratory physician at Liverpool Hospital in Sydney, and is a researcher at Bond University's Institute of Evidence Based Health Care at the Gold Coast University Hospital. Dr Jane Basham and Associate Professor Dr Krishna Sriram work as consultant respiratory physicians at the Gold Coast University Hospital. Dr Sarah Thomas is a medical registrar at the Gold Coast University Hospital. Dr Adem Sav is a senior research fellow and lecturer at the Queensland University of Technology in Brisbane. Associate Professor Rae Thomas and Dr Zoe Michaleff both working for Bond University, Institute for evidence-based healthcare.

(3) What does the study involve?

You will participate in a group meeting or Via Zoom with 8-10 other patients, carers or other doctors like yourself. There are separate groups for patients, carers and doctors. You do not need to prepare yourself before the group meeting. After the meeting we might invite you provide your feedback on the decision aid.

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(4) How much time will the study take?

The group meetings will be conducted at the Gold Coast University Hospital, Block E, Level 2 of the Pathology and Education Building. We may also ask for participation via Zoom meeting if face to face is impractical. Sessions will take between 2 to 3 hours, and you will only be required to attend one session.

(5) Will I incur any costs by participating in the study?

There are no costs associated with participating in this study. Any additional expenses incurred, including travel and parking, will be reimbursed. Catered food will be provided at the meetings. A gift certificate will be awarded for your participation in the study.

(6) Can I tell other people about the study?

You are able to disclose your participation in the study to others, however we request that any information pertaining to other individuals' participation and the content of any group discussions and results to remain strictly confidential.

(7) Will I receive the results of the study?

After the group meetings have concluded, the results of the discussions will be available to the participants. The results from the group meetings will help us develop a tool with the help of a graphic designer which we can use at clinic appointments or at the bedside. The final results of this research project will be published in a medical journal. The findings of this study may also be discussed at conferences and scientific meetings. The tool will become freely available on an online platform for worldwide readership. We will provide you with a copy of the published results, if you are interested.

(8) Confidentiality and disclosure of information

Any information that is obtained in connection with this study that may be identified as in connection with you, will remain confidential and will be disclosed only with your permission, except as required by law. If you consent to participating in this study, we plan to discuss/publish the results in a medical journal, posters/oral presentations at conferences and scientific meetings and the decision aid tool for Queensland Health use. In any publication, information will be provided in such a way that you cannot be identified.

(9) Can I withdraw from the study?

Participation in this study is voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any stage without affecting your relationship with treating doctor. You can withdraw your consent by advising the researcher either verbally, via email, or by completing and returning the 'Participant Withdrawal of Consent Form' that is supplied herein.

When you are taking part in the focus group it will not be possible to exclude individual data once the session has commenced. Any audio recording will be erased, and the information provided will not be included in the study.

(10) How can I obtain further information?

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher A/Prof Claudia Dobler, ph: 02 8738 3000, email: cdobler@bond.edu.au.



(11) What can I do if I have a complaint or a concern?

Any concerns or complaints about the conduct of this study should be directed to the:

HREC Coordinator
Gold Coast University Hospital
1 Hospital Boulevard
SOUTHPORT QLD 4215
Email: GCHEthics@health.qld.gov.au
Phone: (07) 5687 3879

Research Governance Leader
Gold Coast University Hospital
1 Hospital Boulevard
SOUTHPORT QLD 4215
Email: GCHResearch@health.qld.gov.au
Phone: (07) 5687 3880

Please contact the above and quote the HREC reference number HREC/61202.

Any complaint will be investigated promptly and you will be informed of the outcome.

This information sheet is for you to keep.

Research Participant Consent Form

Research Study Title Developing a tool on treatment burden for the patient-physician encounter:
Towards a patient-centred approach in chronic disease care

Researcher's Name Associate Professor Claudia Dobler

Participant Consent

I _____, agree to participate in this research. I have read the Research Participant Information Statement and had any question I have about the research answered for me by the researcher.

Please complete, placing a ✓ in applicable boxes

Name of Research Participant (*First name and Surname*)(Print)

Are you 18 years of age or older? Yes
 No - A parental consent form is required to be completed.

Research Participant Signature

Date

Name of Witness
parent, partner

Relationship of Witness to
Research Participant (*e.g., friend, sibling,*

Witness Signature

Date

Researcher's Signature

Date

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Research Participant - Withdrawal of Consent Form

You can withdraw your participation consent by advising the researcher verbally, via email to cdobler@bond.edu.au or by returning this completed form to Bond University Institute of Evidence Based Practice Professorial Unit, Level 2 PED Building, Gold Coast University Hospital, 1 Hospital Boulevard, Southport, QLD 4215

Research Study Title	Developing a tool on treatment burden for the patient-physician encounter: Towards a patient-centred approach in chronic disease care
Researcher's Name	Associate Professor Claudia Dobler

I hereby **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with the Gold Coast Hospital and Health Service, (*other participating organisation/s or other professional/s*).

Research Participant Name (*Print*)

Research Participant Signature

Date

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29 Sept/21 Renal Physicians							
Round Robin Phase (All the issues identified by participants)	1	2	3	4	5	6	Total
HEALTH SYSTEM ISSUES							21
Time spent in hospital or at home for dialysis	1	1	3		1		6
Frequency of diagnostic and complication monitoring investigations and appointments						5	5
Different goals between clinicians and patients/families, having to choose goals of care, and treatment wishes. Sometimes need to help them understand life-prolonging measures vs. quality of life				2			2
Multiple ongoing appointments with allied health specialists (pharmacists, service access coordinator) and non-health /non-renal services as well can be overwhelming as people have comorbidities							0
Care gets fragmented; patients seen by clinicians in different places, they are not aware of the communication/letters between specialists and other professionals		3		3			6
Cognitive burden due to high demands, understanding of medications, complexity of treatment, navigating the health system, particularly for those with low health literacy			1	1			2
Risk of medication related errors/incidents/complications; chronic care providers can become biased and not see the development of diseases that patients complain often; judgment is clouded							0
Discrimination (medical and otherwise), like being seen as high-risk due to their chronic disease/disability, e.g. Not being admitted to ICU, employment opportunities, clinicians may not always see eligibility and may dismiss certain problems that could be discussed further; and patients may not want to mention to employer they're about to start dialysis							0
Patients with long Hx of disease complications have fear of going to another department/service and being seen by another clinician and not have the same rapport, or information being lost; this concern may be because patient doesn't have the information							0
PSYCHOSOCIAL BURDENS							30
Loss of engagement, opportunities, grieving of future life, very structured life to be able to take all medications	3	2	5		3	4	17
Physical symptoms like breathlessness; high symptom burden where not often possible to control; loss of functionality and few options to address it; tiredness/fatigue hard to deal with; restless leg syndrome also difficult to address			2	5	5	1	13
Relationship stresses, impacted by treatment in the CKD journey, required to bring patients to appointments as a support person; patients can be quite sick and unable to participate in social or family events							0
Irreversible nature of condition is burdensome, impacts on motivation, multitude of symptoms, hard for patients to come to terms with							0
Guilt about impacting on family members, perception that condition is self-inflicted, patients sabotage their own treatment, mood disorders interfere							0
Spiritual effects: patients not being able to attend spiritual services, lose contact with their community and the support that comes with it							0
Loss of freedoms, to travel, to be spontaneous							0
Fear of death knowing life expectancy is short; need to support them to stay alive							0
Discussions about prognosis/realistic life expectancy and therapies are a burden/struggle for patients							0
Burden of transport to/from facility if they can't drive to appointments							0

MEDICATIONS										10
Medication burden: regime complexity, assessing necessity all the time as there can be changes as disease progresses or patients get older; (including transplants patients); easy to not recognise need for deprescribing	4				4				2	10
Patients do not often know who should coordinate their medications, medications dispensed by different people, who owns the final list of medications, who is in charge of telling when medications start/stop; risk to patients from lack of coordination of medication lis										0
Burden of access to dialysis, cosmetic effects, infection risk if done by patients themselves										0
Physical symptoms of haemodialysis, last for hours, severe muscle cramps, headaches, general intolerance										0
Impact of haemodialysis on cognitive and functional decline										0
Medication changes made by different specialists; can be confusing for patients;										0
FINANCIAL										16
Time lost coming to appointments, time on treatment with associated financial hardship	5	4					4		3	16
Patients of low SES are pushed to extreme poverty, transport costs impact on food access even with Centrelink support										0
Insurance premiums go up if patient has chronic disease										
BEHAVIOURAL AND LIFESTYLE CHANGES										13
Dietary restrictions (including dialysis and transplant patients); Fluid intake, sodium, potassium, phosphate; Patients have comorbidities like diabetes, so also other restrictions compounding	2	5	4					2		13
TRANSPLANTS										0
Preventative measures related to transplantation: changing lifestyle, preventing infection, bone protection, malignancy screening, managing CVD risk factors; new dietary restrictions and medications										0

Session date	Patient treatment burden topics	Participants								TOTAL
		1	2	3	4	5	6	7	8	
	BEHAVIOURAL AND LIFESTYLE CHANGES									26
26/2/21	Lifestyle changes including dietary restrictions		4		2	2		2		10
9/3/21	Negative impact of treatment on lifestyle, diets, socialising, inability to travel, poor sleep, side effects of medication	3	3		5		5			16
	EXPERIENCES WITH ANCILLARY SERVICES									5
26/2/21	Food choices during treatment		2	3						5
	FINANCIAL BURDENS									23
26/2/21	Cost of medication, losing appointments, accommodation for transplant, parking, future medication cost					3	3	5		11
9/3/21	High cost of medication, electricity, water bills, dialysate treatment bags		1	1						2
17/6/21	Costs of treatment and out of pocket expenses (including medication, petrol and parking) is difficult on the pension. Home dialysis patients have some added costs (medication) which are not subsidised whereas these costs do not incur for centre-based dialysis patients.	4	1	2		3				10
	HEALTH SYSTEM ISSUES									111
26/2/21	Continuity of care, seeing the same doctor, consistent information about medication and conditions	3			4					7
9/3/21	Poor communication across occupational groups and treatment centres, accessing information from clinical record	5	4	3		3				15
9/3/21	Non-renal clinicians lack of specialists knowledge of renal patient's issues & patients having to repeat/advocate leading to waiting times in ED		2	5	3	5				15
9/3/21	Lack of continuity of care/consistency, using several doctors who have different perspectives	4				4				8
17/6/21	Early identification and timely support from allied health (e.g. social workers) is vital to sustain treatment. More support to find suitable accommodation for home dialysis patients is required as this will save the hospital money.	2		5	3					10
17/6/21	Continuity of care from health professionals/allied health is important especially around chronic conditions with unique issues like home dialysis. Case management may be required.	1		4	2	1				8
26/2/21	Flexibility in choice, timing and location of treatment (seeing alternative doctors if needed at the time that suits e.g. dialysis am/pm)	4	3	1	3		1	4	5	21
26/2/21	Travelling to access treatments because no specialists near home		1				2		1	4
26/2/21	Waiting times for treatment, procedures, waiting all day, persistent problems like potassium/BP, update on progress while waiting					4				4
17/6/21	Treatment access and burden of appointments is taking time away from more important activities (including appointments on different days, time to wait for specialists, living away from treatment centre, multiple appointments with different specialists in different centres).	5	5	1	4	4				19
	MEDICATION BURDENS									18
26/2/21	Obtaining scripts are difficult. Low number of doctors who prescribe, need a central system			4		1			4	9
9/3/21	Changes of medication & pharmacists. Medication prescribed or substituted without explanation	2	5	2						9
	PATIENT AND FAMILY COMMUNICATION AND INFORMATION									41
26/2/21	Need for information about treatment options, side effects, test results	2			5					7
26/2/21	Doctors being honest telling patients empathically & showing that they care	5	5		1				2	13
26/2/21	Involvement of family in treatment/ partners in care	1		2			5		3	11
9/3/21	Need for more information on treatment options, rebates for medication, signs that require ED treatment					2				2
17/6/21	People outside of the illness (even family members) do not understand the condition and treatment. Families need to be informed and educated about the treatment and disease.		2		1					3
17/6/21	Information around transplant waiting list is misleading and communication/coordination between clinicians can be lacking.		3			2				5

PSYCHOSOCIAL BURDENS ON PATIENTS AND FAMILIES									58
26/2/21	Social/ emotional/financial impact on family			5			4	1	10
26/2/21	Treatment regime, fatigue, frequency of dialysis, impact on employment					5		3	8
9/3/21	Impact beyond patients, on significant others			4	4	1	3		12
9/3/21	Emotional impact , frustration, depression/anxiety, inability to continue sudy	1			1		4		6
9/3/21	Availability and delivery of equipment/resources and needing help from other				2				2
17/6/21	Emotional and physical burden and adjustment to treatment (including dialysis) is difficult on patient and family (e.g. stopping and returning back to employment, moving closer to hospital, making permanent life changes)	3	4	3	5	5			20

Question 1:**What issues related to patients' burden of treatment do you think should be discussed between doctor and patient?**

Please write down your responses to this question below (without discussing them with anyone). You can write down as many issues as you like.

Question 2:**What do you think are potential solutions to reduce treatment burden for patients that should be discussed between doctor and patient?**

Participants were encouraged to discuss potential solutions to the top five ranked treatment burden issues.