



# BMJ Open Clinicians' perspectives on equity of access to dialysis and kidney transplantation for rural people in Australia: a semistructured interview study

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## ABSTRACT

**Objectives** People with chronic kidney disease requiring dialysis or kidney transplantation in rural areas have worse outcomes, including an increased risk of hospitalisation and mortality and encounter many barriers to accessing kidney replacement therapy. We aim to describe clinicians' perspectives of equity of access to dialysis and kidney transplantation in rural areas.

**Design** Qualitative study with semistructured interviews.

**Setting and participants** Twenty eight nephrologists, nurses and social workers from 19 centres across seven states in Australia.

**Results** We identified five themes: *the tyranny of distance* (with subthemes of overwhelming burden of travel, minimising relocation distress, limited transportation options and concerns for patient safety on the roads); *supporting navigation of health systems* (reliance on local champions, variability of health literacy, providing flexible models of care and frustrated by gatekeepers); *disrupted care* (without continuity of care, scarcity of specialist services and fluctuating capacity for dialysis); *pervasive financial distress* (crippling out of pocket expenditure and widespread socioeconomic disadvantage) and *understanding local variability* (lacking availability of safe and sustainable resources for dialysis, sensitivity to local needs and dependence on social support).

**Conclusions** Clinicians identified geographical barriers, dislocation from homes and financial hardship to be major challenges for patients in accessing kidney replacement therapy. Strategies such as telehealth, outreach services, increased service provision and patient navigators were suggested to improve access.

## INTRODUCTION

It is estimated that 44% of the world's population live in a rural area.<sup>1,2</sup> People with chronic kidney disease (CKD) requiring kidney replacement therapy in rural communities have a higher risk of mortality, morbidity, hospitalisation and a higher burden of disease compared with people in urban locations, though the rates vary depending on modality, degree of remoteness and country.<sup>2–10</sup> Access

## Strengths and limitations of this study

- Diverse range of clinicians took part in in-depth interviews, including nephrologists, social workers and nurses from a broad range of healthcare settings in geographically diverse locations.
- Australia has universal healthcare provided, which may limit the transferability of the findings to other healthcare settings.
- Some interviews sought were unable to occur due to commencement of COVID-19, with most interviews from that point being via videoconferencing or the telephone.

to all forms of dialysis and kidney transplantation for rural patients can be challenging due to late referral and limited local availability of specialist nephrology services.<sup>4 11–14</sup> As a consequence, rural patients are less likely to be placed on the transplant waiting list (8%–15%) than those in urban areas and more likely to use peritoneal dialysis or in-centre haemodialysis initially.<sup>11 13 15–18</sup>

Many barriers to all modalities of dialysis and transplantation exist for rural patients with CKD, including but not limited to geography and travel, particularly in large countries such as Australia, Canada and the USA.<sup>2 11 19–25</sup> Compounding the complexities in accessing healthcare is substantial out of pocket expenses, with some patients unable to afford transport and accommodation to attend specialist appointments, home training facilities and transplantation centres which are increasingly located in urban centres.<sup>3 9 12–16</sup> Lower incidence rates of initiation of dialysis, particularly home haemodialysis, in rural populations occur in many countries, coupled with an increasing centralisation of training facilities in urban areas.<sup>3 7 11</sup> There is also a higher incidence of



relocation in rural/remote patients attending incentive haemodialysis compared with transplant patients.<sup>14</sup> It is estimated that 28.7% of patients with CKD requiring kidney replacement therapy in Australia reside in rural areas.<sup>11</sup> It is difficult to know the exact percentages of Indigenous Australians requiring kidney replacement therapy due to relocation, we do know that Indigenous Australians living in remote areas have a 20 times higher rate of end-stage kidney disease (ESKD) than those in urban areas.<sup>26</sup>

These geographical disparities mean that clinicians encounter unique challenges in providing care for rural patients with CKD, however, little is known about their perspectives across all modalities of kidney replacement therapy. This study aimed to describe the perspectives of clinicians on equity of patient access to dialysis and transplantation in rural communities, to inform strategies to maximise access to quality care, and thereby reduce disadvantage, inequity and improve health outcomes.

## METHODS

We followed the consolidated criteria for reporting qualitative research framework.<sup>27</sup>

### Context

In Australia, approximately 29% (7 million) of the population live in rural areas.<sup>2</sup> Australia has a universal public health insurance scheme, but for some medical appointments and tests, there can be a gap payment required to be paid by the patient.<sup>28</sup> In 2009, a range of health initiatives were introduced for our Indigenous Peoples to address disparities in access to health and education, commonly known as the 'Closing the Gap' policy and funding that assists to reduce out of pocket expenses for Indigenous people.<sup>29</sup> The delivery of transplant care in Australia is via a hub-and-spoke model with all services in major urban areas.<sup>30</sup>

### Participant selection and setting

Nephrologists, nurses and social workers involved in the care of rural patients with CKD in Australia were eligible. Australia has universal healthcare coverage insurance available in all states and territories. We used purposive sampling to include maximum diversity of characteristics based on demographics (age, sex, geographic location) and role and experience. Clinicians from all states of Australia were represented and 78% of clinicians were in a rural health service or provided physical outreach services regularly to a rural health service. A snowballing technique was also used, whereby participants could nominate other clinicians who they believed could offer a different and relevant perspective about disparities in access to kidney replacement therapy in rural communities. Invitations were sent by standardised email through the investigator's professional networks. Written consent was obtained for each participant.

## Data collection

Author NJS-R conducted semistructured interviews with each participant from December 2019 to May 2020. The interviews were conducted face-to-face, over the phone or via videoconference. The interview guide (online supplemental appendix table 1) was based on a literature review of patient and clinician perspectives on access to kidney replacement therapy and discussion among the research team.<sup>31</sup> In the interviews, access was defined and discussed in terms of the opportunity to obtain appropriate health-care services and receive relevant information pertaining to their patients' health issues.<sup>32</sup> We acknowledge that the definition for 'rural' varies and may be based on characteristics of a community, availability of health resources and education among other things.<sup>33–35</sup> In our study, we defined 'rural' to include all areas outside of major cities.<sup>36</sup> Interviews were audio recorded and transcribed verbatim. We conducted interviews until data saturation was reached and no repeat interviews were required.<sup>37</sup> NJS-R was known to some of the participants interviewed, as they had been a part of her medical team.

## Analysis

Using thematic analysis,<sup>38</sup> the transcripts were imported into HyperRESEARCH (V.4.0.1 (ResearchWare Randolph, Massachusetts) and author NJS-R read transcripts and inductively identified preliminary concepts and grouped similar concepts into initial themes and subthemes. These were reviewed and discussed with AT and TG. The transcripts were coded line-by-line by NJS-R and conceptual links and patterns within the data identified. The preliminary findings were sent to participants and their feedback was integrated into the final analysis. Investigator triangulation and member-checking helped ensure the findings reflected the full range and depth of the data.

## Patient and public involvement

First author NJS-R and IR have lived experience of both dialysis and kidney transplantation and reside in rural communities. NJS-R conceived the idea for this study, conducted the interviews, data collection, coding and analysis and drafted the manuscript. NJS-R is currently a PhD student with experience in qualitative research.

## RESULTS

Of the 28 participants, 13 (47%) were nephrologists, 11 (39%) were nurses and 4 (14%) were social workers (table 1; participant characteristics). Thirteen (45%) were practising primarily in a rural setting, 9 (31%) provided outreach services to rural locations from an urban hospital and 6 (22%) provided care for patients from rural locations in the urban setting only. Ten (36%) of the interviews were conducted face to face, 10 (36%) using videoconferencing and 8 (28%) were conducted by telephone. The mean duration of the interview was 29 min.

**Table 1** Participant characteristics (N=28)

Characteristics	N (%)
<b>Participants</b>	
Nephrologist	13 (47)
Nurses	11 (39)
Social worker	4 (14)
<b>Sex</b>	
Female	20 (72)
Male	8 (28)
<b>Age</b>	
31–40	10 (36)
41–50	9 (32)
51–60	8 (28)
61–70	1 (4)
<b>Location</b>	
Rural	13 (47)
Urban but provide rural outreach	9 (31)
Urban only	6 (22)
<b>State</b>	
New South Wales	13 (46)
South Australia	5 (18)
Queensland	3 (11)
Western Australia	2 (7)
Tasmania	2 (7)
Victoria	2 (7)
Northern Territory	1 (3)
<b>Years of experience</b>	
Less than 10	2 (7)
10–20 years	12 (43)
21–30 years	11 (39)
30+ years	3 (11)
<b>Location of interview</b>	
In Person	10 (36)
Zoom	10 (36)
Phone	8 (28)

We identified five themes: the tyranny of distance, supporting navigation of the health systems, disrupted care, pervasive financial distress and understanding local variability. The respective subthemes are described in [figure 1](#), which shows the conceptual links among the themes. Selected illustrative quotations to support each theme are provided in [table 2](#) (illustrative quotations).

### The tyranny of distance

#### Overwhelming burden of travel

Participants were concerned about the strain on patients in ‘travelling over 200 km/day just to access haemodialysis, three times a week’. They remarked that this ‘creates a very heavy medical model for these patients’ particularly

if complex medical issues arose, whereby patients would have travel to the urban hospital. They noted that some rural patients ‘just don’t know how they are going to get’ to the urban transplant centre if they were offered a deceased donor kidney transplant, as they would have to coordinate and mobilise resources to relocate at short notice.

#### Minimising relocation distress

Home dialysis training and transplantation were seen to ‘require a big dislocation for a significant period of time for rural patients’. Participants were concerned that their patients had to leave known networks and services to access treatment, and that added stress to already vulnerable patients, particularly as many had never left their local area or travelled on an aeroplane. Clinicians emphasised that for Indigenous Australian patients, relocation was particularly difficult as they had strong ties with their community and did not want to ‘leave their home, their family, their support system for 2 months to go to this place’. Most strived to ‘get people back home as soon as possible and keep them at home as much as possible’; however, they acknowledged that this was not always possible.

#### Limited transportation options

Participants in rural areas noted the ‘limited transport options’ in their area, particularly for ‘people who don’t drive or with people with disabilities’. In one instance, a patient paid ‘AU\$600 return trip’ by taxi to attend an urgent procedure 125 km away as all other transport options had been exhausted. Permanent relocation to a larger centre to access haemodialysis was seen as the only option for those who did not have reliable, long-term transport to attend dialysis three times a week for extended periods.

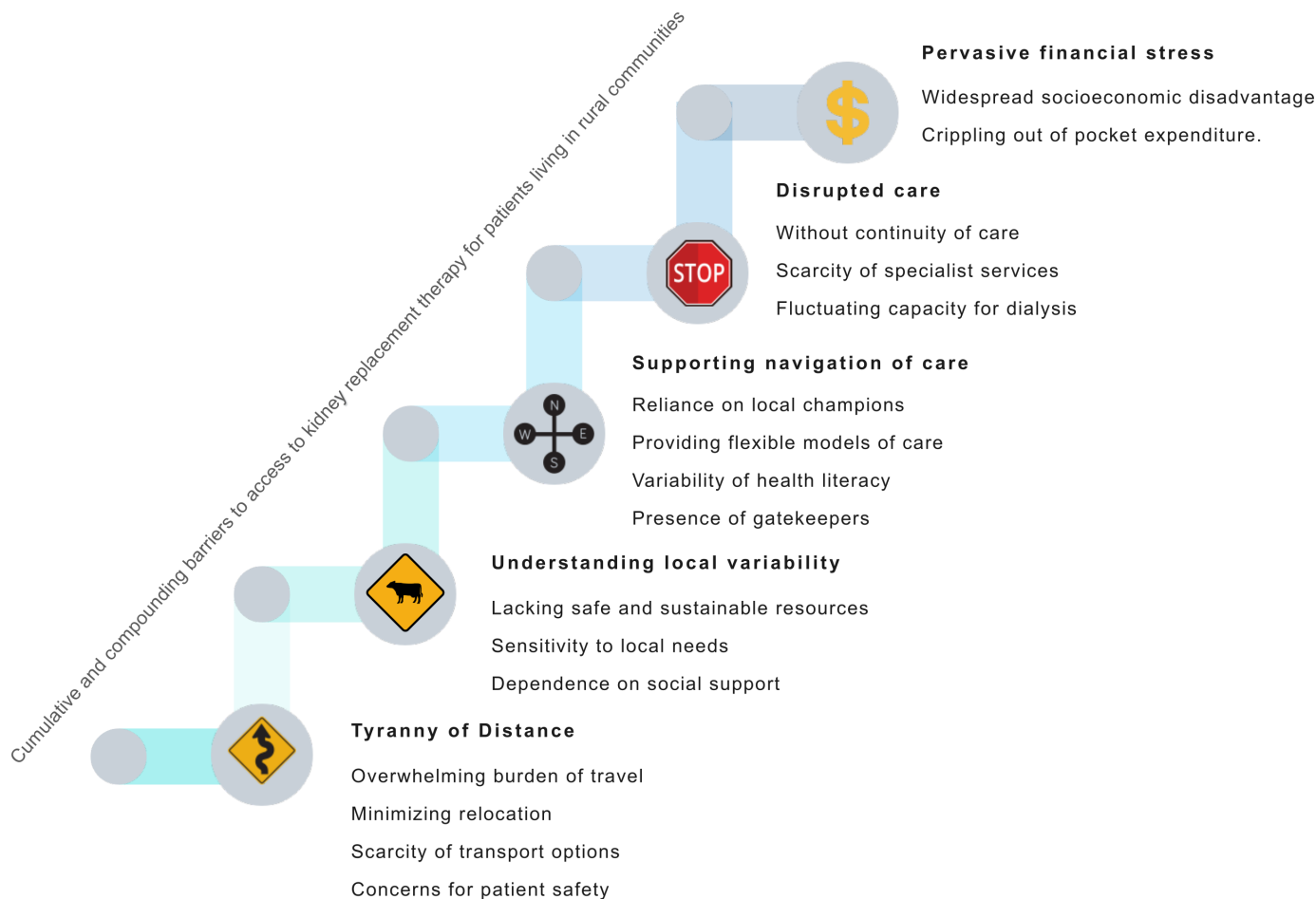
#### Concerns for patient safety on roads

Some worried about the safety of their patients who drove long distances, and some ‘had patients die on the road’ while travelling to receive treatment and were aware of driver fatigue and that ‘the roads are dangerous’. To minimise unnecessary driving clinicians actively supported flexibility, such as scheduling appointments outside normal clinic hours if patients were in town for other appointments or tests or used telehealth where possible.

### Disrupted care

#### Without continuity of care

The high turnover of general practitioners and nursing staff were reasons cited by participants for low rates of referral to nephrologists, and lack of continuity of care in dialysis in the rural setting. One participant noted that in some areas, nurses only worked ‘between 4 and 6 months in a remote community’ before moving on. Some were ‘burnt out’ because of high turnover and shortage of suitably qualified clinical staff.



**Figure 1** Thematic schema.

### Scarcity of specialist services

Participants were conscious that patients had very limited access to vascular access surgery for dialysis and stated that most rural patients were required to attend hospitals in urban areas. They were frustrated as transplant ‘workup is harder for country people’ due to difficulty in finding and affording locally available services such as dentistry, allied health and bariatric surgery to enable them to be wait listed for a transplant. Some believed that surgeons in rural areas were more conservative and ‘tend to get quite scared of someone whose glomerular filtration rate (GFR) is 10’ and would not operate locally, referring patients to a larger centre for a procedure, further increasing the patients travel and financial burden.

### Fluctuating capacity for dialysis

Participants felt helpless in seeing patients unable to ‘access a (dialysis) chair in their hometown’. Patients were required to travel long distances to the nearest available chair or had to opt for home dialysis modalities even if the clinicians believed that in-centre dialysis was a better treatment option for the patient’s well-being. Sometimes, it was a lack of suitably qualified nurses that meant patients needed to travel to a distant town to receive dialysis.

### Supporting navigation of health systems

#### Reliance on local champions

Participants providing outreach services relied heavily on local clinicians to coordinate patient care locally, to advocate for their patients and to proactively encourage attendance at appointments and treatment. Local advocacy for patients was considered vital to improve access to all forms of kidney replacement therapy, and they were concerned that the reliance on one clinician was not sustainable and issues with ‘succession planning’ may lead to gaps in service provision and loss of the local advocate.

#### Providing flexible models of care

Participants believed that rural patients’ access to specialists was limited under the current models for service provision. Patients were often unwell and lacked resources to travel, and the limited and inflexible specialist outreach programmes to rural areas placed unfair burden on rural patients and their families. Examples of alternate approaches included ‘home training in the home’ and workup testing for transplantation be commenced prior to dialysis to minimise the problems and burden of travel after dialysis.

Table 2 Illustrative quotations	Quotations
<b>Theme</b> The tyranny of distance	<p>Overwhelming burden of travel            'a lot of people in Sydney don't actually appreciate that Moree is in fact seven hours from Sydney. I've had vascular surgeons actually get people down to sign a consent form to Newcastle, just to sign on the consent form for an operation I know they're going to have, so they have to travel for another six hours to get there' (Nephrologist) 'Even when I went to the Bush, I still had people traveling an hour, two hours to get to me.' (Nurse)</p>
Minimising relocation distress	<p>'Well from a point of view of helping people to get to home dialysis, which then would hopefully for those people that have got the tyranny of distance, more equality with them having actual designated accommodation, designated assistance' (Nurse). 'The significant relocation and needing to look after yourself, care for yourself, manage your appointments, have that ongoing kind of ability to orientate yourself in a new city with anxiety, deal with stress, people with pre-existing psychiatric diagnoses and management of conditions' (Social Worker). 'the problem with that is that still from PD catheter insertion to going home still works out to be about at least three months' (Nephrologist)</p>
Scarcity of transportation options	<p>'if people had no suitable transport, then yes, they had to move.' (Nurse) 'You've got no car, no reliable means, finances, whatever, to get in and out (to dialysis).' (Nurse) 'But for patients that are wheelchair bound, there's a \$300 taxi ride down there and a \$300 taxi ride back and I don't know many people that could afford' (Nurse)</p>
Concerns for patient safety	<p>'but she wasn't safe to drive, so she had to move here and drive back on the weekends. It was very suboptimal' (Nephrologist). 'we do have a couple of patients that do drive themselves. And this guy turns up the other day and he had basically done something to two tyres. He hits something. He doesn't know what he hit, he doesn't know where, he doesn't know anything. That was a bit of a concern' (Nurse). 'We know the roads are dangerous. No one wants to drive unnecessarily' (Nurse).</p>
Supporting navigation of health systems	
Reliance on local champions	<p>'it's that issue of the corporate knowledge of one person and then that person finishes [work] like this home hemo person. And then just, you lose so much information when they go' (Nephrologist) 'So, we're doing everything by telemedicine and without CNC on the ground up there it would be impossible.' (Nephrologist) 'So, just actually having leadership publicly outed as, as having a kidney transplant.' (Nephrologist)</p>
Providing flexible models of care	<p>I, think just changing the paradigm...and trying to provide services locally is important, and not the attitude that has to be done in the city.' (Nurse) 'the idea of this hub and spoke model where we would send them to Sydney for everything and we're just sort of a band aid service. I don't think that that's gonna work.' (Nephrologist) 'he works from the land. He's supporting a family; he doesn't have the time to come down here and catch up with me. And that's one example of where if we had a bit more assistance, we could do these visits to the country or rural areas.' (Nephrologist)</p>
Frustrating presence of gatekeepers	<p>'People who are the gatekeepers to allowing patients to access the hospital accommodation. We need to have accommodation in the Bush for traveling patients' (Social Worker). 'They have to go from hospital to hospital. They're the rules. So therefore, you admit them into the hospital to get them down there to try and do the right thing by them. But then that's not always guaranteed because you've got to have a hospital bed'. 'trying to arrange transport' (Nurse).</p>
Variability of health literacy	<p>'Our use of medical jargon and just being able to communicate on their level that they can understand, we struggle with that as health providers. We don't have the experience to know what's the most appropriate way of bringing across messages' (Nephrologist). 'I think literacy is an issue for the indigenous patients. You can send them a letter to come to clinic, but you need to ring them and then you need to get onto perhaps the AMS.' (Nurse) 'I think 50% of our patients they've got a good understanding, but once you start drilling down, they actually don't have a very good understanding. it's like Groundhog Day. But you actually know that you've addressed that three months ago.' (Nurse)</p>

Continued

Table 2 Continued

Theme	Quotations
Disrupted care	
Without continuity of care	'The GPs are quite transient. So, you might get a great GP. And though they'll develop a relationship with a patient and become really engaged and will contact you. But when they move on and they do move on, because there are a lot of travelers, or they get burnt out.' (Nurse) 'You know, we're currently having to train more staff up in dialysis, but you don't have any idea whether those staff are going to actually stay on or enjoy dialysis at all' (Nephrologist).
Scarcity of specialist services	'Allied health busy all the time. As you could imagine with dialysis patients it's much more difficult to access if you live in a really small community.' (Social Worker) 'We don't have a transplant surgeon. We don't have a transplant surgeon. So, when we've got complicated patients, we've had to send a number of people to Melbourne.' (Nephrologist) 'So, the middle-aged Aboriginal men in their 50s are just struggling to try and help them lose weight and the services available for them to do that. Non-existent.' (Nephrologist)
Fluctuating capacity for dialysis	'Actually, having chairs available, I think about a chap that I was wanting to start on dialysis who was blind and, in a wheelchair, and our nearest chair was going to be over an hour away' (Nephrologist). 'They can't actually have it in their home town. They actually have to travel to somewhere else, look at a home therapy or something else. It's not the way dialysis is set up. It's like a hospital when it goes on bed block, when the dialysis unit in the local town is overwhelmed' (Nurse).
Pervasive financial distress	
Crippling out of pocket expenditure	'if you want to get an echo done, you've got to see someone privately and it's not done through the hospital system and then you've got to come up with money' (Nephrologist). 'I know that I've got one complicated patient who's had a whole lot of surgical complications post-transplant. And he told me the other day and it actually made me gasp that him and his wife, both on the Pension \$20 000 in the red over the last two and a half years' (Nephrologist). 'Oh, well I need a root canal and I don't have X number of thousands of dollars; therefore, I can't have my transplant because I cannot get dental clearance' (Nephrologist).
Widespread socio-economic disadvantage	'they won't tell you they can't afford it, and they're proud' (Nephrologist). 'So, if you think about it, hemodialysis is like a part time job really. You keep committed three times a week. And with PD it's like a newborn child. And a lot of people can't work.' (Social worker)
Understanding local variability	
Sensitivity to local needs	'people in rural areas have pretty much not going to come to the doctor until they're sick. Males definitely.' (Nephrologist) 'I think the stigma around it's a big one as well. And within like, do you feel within rural communities where other people are more aware maybe of people are more aware of what's going on with people and so confidentiality's really hard in small towns.' (Social Worker) 'There is all sorts of cultural barriers if you have a look at the indigenous population' (Nephrologist)
Dependence on social support	'If someone doesn't have the support net you know, that is actually a very serious barrier to transplant'. (Nephrologist) 'it's difficult for these patients who live alone, and don't have a lot of support, so they're the ones who really find it difficult.' <sup>61</sup> 'They have to take carer sometimes, but that carer is often the carer for other people back on Country. So, you know that becomes difficult as well. And then they will just get the pips with having to stay in XXX for so long.' (Nurse)
Lacking availability of safe and sustainable resources for dialysis	'The problem is in the wet where they're isolated you have to store five- or six months' worth of supply' (Nurse). 'We've got a patient at the moment, who we've trained on peritoneal dialysis, but he's currently in Brisbane living with his daughter because we just can't get supplies to him' (Nephrologist). 'Water quality, especially off the back of the drought. We have had a patient who wanted to do home hemo and we were breaking ROs trying to purify the water to the point where she could do it' (Nurse).

### Variability of health literacy

Some acknowledged a 'disparity between health literacy with country versus city people', and that this was most evident in culturally and linguistically diverse groups. They were concerned about the lack of culturally appropriate material, particularly for Indigenous Australians and some felt they were 'not equipped' and did not have the time or skills required to provide a 'proper education of peoples with different... understandings of health'. Participants felt helpless knowing patients were disempowered, unable to make decisions and relied heavily on the clinician's recommendations to make decisions.

### Frustrated by gatekeepers:

Participants were exasperated by 'barriers (faced) everyway you go'. They speculated that transport and accommodation for patients requiring kidney replacement therapy was not a high priority for health service providers. They suggested changes such as 'a nurse led renal clinic' but were exasperated by 'management' who would not consider or approve recommendations for changes to outreach services to alleviate travel-related burden on patients.

### Pervasive financial distress

#### Widespread socioeconomic disadvantage

A large proportion of rural patients were observed to be 'incredibly poor', 'poorly educated' and in the midst of a 'housing crisis'. Clinicians were aware of cascading consequences, whereby patients were unable to work due to constraints of dialysis, which led to financial difficulty in having to pay for petrol to drive to treatment, and patients 'losing weight because they did not have quite enough money to eat'. Due to overcrowding in some patient's homes, home dialysis was not an available option due to the significant space required for storage of medical equipment and supplies. The increasing homelessness in certain rural areas was considered to be alarming, compounding complex medical and social issues, leading to very limited options for kidney replacement therapy.

#### Crippling out of pocket expenditure

Participants noted that patients had difficulty attending home dialysis training located in other towns, as they could not afford the financial outlay for accommodation and transport, or their caregiver could not afford to take leave from work as this would leave them with no income for that period. Participants felt hamstrung as they witnessed patients unable to obtain dental clearance or cardiac testing to be waitlisted for transplant, languishing on dialysis and being unable to move towards transplantation.

### Understanding local variability

#### Lacking availability of safe and sustainable resources for dialysis

Participants explained that some patients were unable to choose to do home haemodialysis because they had poor 'water quality and energy supply'. Lack of storage capacity for essential supplies for home dialysis in some patient

households and remote communities presented difficulties in ensuring consistent availability, and left clinicians feeling frustrated, with no choice but to refer patients to do in-centre dialysis or relocate to where supply could be guaranteed.

### Sensitivity to local needs

Participants remarked on the lack of 'resources and infrastructure' in rural areas, which required them to be acutely conscious of service availability. They were aware of patient concerns regarding protection of privacy and confidentiality, as some patients were concerned about the 'stigma' associated with their treatment, especially in small communities, where privacy is harder to maintain.

### Dependence on social support

A lack of support 'from family or friends of patients' was found to be a major hurdle to accessing home dialysis and transplantation. For in-centre dialysis, transportation requirements that could 'go on for years' were difficult to maintain without the presence of family and friends. Home dialysis training, which required both patient and caregiver to attend for a period of up to 3 months, was particularly difficult for Indigenous Australian patients and those with younger families, especially where the caregiver had responsibilities towards more than one person at a time.

## DISCUSSION

The cumulative and compounding barriers to kidney replacement therapy that patients from rural communities faced, as identified by clinicians, including limited transport options that often required patients and their families to relocate to larger centres, limited outreach services, particularly in relation to transplantation and centralisation of dialysis and home training facilities. Clinicians noted that patients had limited choices regarding treatment modality, based on the availability of qualified nursing staff, dialysis chairs, essential supplies and a safe, sustainable water supply. Clinicians feared for patients from rural areas with inadequate social support who faced challenges in navigating and accessing the best available treatment options. Further complicating access to dialysis or a transplant was ongoing out of pocket expenses that included, petrol, accommodation, time off work for themselves and a caregiver, specialists fees and dental costs that patients could not afford, particularly with regards to being wait listed for transplantation.

There were some differences in perspectives based on the participant's role and location. Social workers and nurses emphasised the financial burden and dependence on social support, particularly among patients from low socioeconomic backgrounds. Clinicians who worked or provided outreach services in very remote communities expressed the need for culturally appropriate educational material for Indigenous patients and their families where

**Table 3** Suggestions for addressing disparities in rural access to kidney replacement therapy

Domain	Suggestions
Minimise travel	<ul style="list-style-type: none"> <li>▶ Encourage telehealth appointments in conjunction with face-to-face appointments where necessary.</li> <li>▶ Minimise essential trips by health services coordinating appointments.</li> <li>▶ Develop programmes to increase availability of home dialysis training and the infrastructure required by patients.</li> </ul>
Provide access to financial support	<ul style="list-style-type: none"> <li>▶ Work with stakeholder organisations including government and charity organisations to establish funding specifically for rural patients to access dialysis and transplantation.</li> <li>▶ Simplify Government assistance programmes for travel and accommodation reimbursement schemes.</li> <li>▶ Offer financial counselling services for patients and their families.</li> </ul>
Minimise need for relocation	<ul style="list-style-type: none"> <li>▶ Use of telehealth to assist with return of patients home post-transplant as soon as reasonable.</li> <li>▶ Offer home dialysis training in the patient's home—trainers would go to the patient and family for at least part of the training.</li> <li>▶ Coordinate accommodation for kidney related treatment at major hospitals for rural patients and their families.</li> <li>▶ Increase the availability of satellite units in rural towns that are currently unserved.</li> <li>▶ Establish community-based self-care haemodialysis units that are unstaffed.</li> </ul>
Rural workforce issues	<ul style="list-style-type: none"> <li>▶ Establish or increase frequency of outreach or mobile clinics (for medical consultations, transplant work up testing, culturally targeted education and dialysis).</li> <li>▶ Increase access to telehealth appointments where possible.</li> <li>▶ Train and upskill dialysis nurses for rural areas</li> </ul>
Provide support for patients in navigating multiple health services	<ul style="list-style-type: none"> <li>▶ Implement and evaluate patient navigator programmes for CKD in rural settings.</li> <li>▶ Development by patients of rural based patient information packs with resources and information to encourage self-management and improve education regarding their local health services.</li> </ul>
Ensure access to allied health professionals	<ul style="list-style-type: none"> <li>▶ Use of telehealth to provide these services particularly in social work, psychologist and dietetics.</li> <li>▶ Provide education for patients and their families as to service availability and financial assistance to access these services (ie, Chronic care plans, Mental healthcare plans)</li> </ul>
Provide culturally and rural specific education for dialysis and transplantation	<ul style="list-style-type: none"> <li>▶ Provide education in video format developed with consultation of Culturally and linguistically diverse groups.</li> <li>▶ Incorporate patient experiences into all patient education to encourage sharing of stories and patient led transfer of knowledge to others.</li> </ul>

CKD, chronic kidney disease.

English was often a second language, there was a large variability in the remote areas of the primary language.

There have been limited qualitative studies investigating health professionals' views on equity of access to all forms of kidney replacement therapy for rural patients, and those that are available focus primarily on disparities in access based on ethnicity and Indigeneity<sup>22 39</sup> or have been focused on one type of kidney replacement therapy.<sup>21</sup> We have included all modalities of kidney replacement therapy and health professionals from multiple disciplines and all states of Australia. Our findings have generated additional and broader learnings that cover many areas of inequity of access for rural patients, particularly with regards to transportation, relocation requirements and financial burden.

We generated diverse and detailed insights from multi-disciplinary clinicians on disparities in access to kidney replacement therapy in patients in rural communities. However, there are some potential limitations. The interviews were conducted in Australia and the transferability of some of the concepts in our study to other settings is

uncertain, particularly to low- and middle-income countries, and settings without universal healthcare insurance. Only a small number of social workers were included; however, we were able to achieve data saturation overall. Also, some interviews that were sought were unable to occur due to commencement of COVID-19, with most interviews from that point needing to be done via video-conferencing or the telephone due to travel restrictions. Some of the issues raised may also be experienced by those in urban settings, however, patients in rural areas have additional distances to travel (tyranny of distance) and have more out of pocket expenses (pervasive financial distress) because of the need to pay for travel and accommodation that are not typically needed for patients in urban areas.<sup>40 41</sup>

Our findings can inform the development of strategies to improve access to kidney replacement therapy for patient in rural communities, through decreasing travel burden, minimisation of relocation and reducing out of pocket expenses of the patients. These have been shown in [table 3](#) (suggestions for addressing disparities in



rural access to kidney replacement therapy) along with some possible suggestion to address these issues. There is a need to increase outreach clinics to alleviate some of the travel and financial burden on the patients and their families. This would be vital not only for transplantation assessment but also for home dialysis, as both modalities currently require patients to travel long distances to larger urban centres.<sup>22 42 43</sup> Flexibility of care provision through use of telehealth for pre and postsurgical appointments needs to be considered.<sup>44</sup> To further mitigate the barriers imposed by geography, telehealth can decrease patient expenditure on travel-related expenses, reduce health system costs and minimise time required to attend appointments by patients.<sup>44–49</sup>

Patient navigator programmes have been implemented in rural and disadvantaged populations successfully in patients with cancer, to overcome barriers to access to healthcare for these patients.<sup>50 51</sup> It was also identified by Australian Indigenous patients with CKD and cancer as a priority to assist with improving access.<sup>52 53</sup> To date, there is limited availability of research in the effectiveness of rural patient navigators for improving access and further work is needed to develop this role for this population and how the role of a rural navigator will differ to those in urban centres.<sup>54</sup> Patient navigator roles can vary greatly, but from the findings of this study, we believe that those roles should include assisting with coordination of care, health literacy and CKD education support, practical support to assist with accommodation and transport issues, particularly in those with little or no social support, and to be able to provide these services through telehealth where possible.<sup>54–56</sup>

Financial burden is a well-recognised barrier to accessing dialysis and transplantation and has been identified in previous studies, however, there is limited literature available as to the extent in rural patients and how best this could be addressed.<sup>22 56–59</sup> We suggest further studies to evaluate the economic hardship experienced by rural patients and their families requiring kidney replacement therapy. Alternate models of care have been suggested to improve access and may alleviate the financial burden on patients, and these include increased use of home dialysis modalities, telehealth, provision of satellite or community-based haemodialysis and increased outreach services by specialists, particularly in relation to vascular access and transplantation.<sup>22 24 42 60</sup>

Clinicians were concerned regarding the difficulties faced by their rural patients requiring kidney replacement therapy. The areas where they reported inequitable challenges particularly pertained to geographical barriers and the resulting periods of dislocation from their homes, the pervasive presence of financial hardship to access appropriate care and the difficulties patients faced navigating complex and often, multiple health services. Suggested strategies to decrease disparities in accessing care included increased use of telehealth for consultations, increased allied health and specialist outreach

services to rural areas and provision of patient navigators within the health services.

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