

# BMJ Open Patients' and caregivers' perspectives on access to kidney replacement therapy in rural communities: systematic review of qualitative studies

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## ABSTRACT

**Objective** Patients with chronic kidney disease (CKD) requiring kidney replacement therapy (KRT) in rural communities encounter many barriers in accessing equitable care and have worse outcomes compared with patients in urban areas. This study aims to describe the perspectives of patients and caregivers on access to KRT in rural communities to inform strategies to maximise access to quality care, and thereby reduce disadvantage, inequity and improve health outcomes.

**Setting** 18 studies (n=593 participants) conducted across eight countries (Australia, Canada, the UK, New Zealand, Ghana, the USA, Tanzania and India).

**Results** We identified five themes: uncertainty in navigating healthcare services (with subthemes of struggling to absorb information, without familiarity and exposure to options, grieving former roles and yearning for cultural safety); fearing separation from family and home (anguish of homesickness, unable to fulfil family roles and preserving sense of belonging in community); intense burden of travel and cost (poverty of time, exposure to risks and hazards, and taking a financial toll); making life-changing sacrifices; guilt and worry in receiving care (shame in taking resources from others, harbouring concerns for living donor, and coping and managing in isolation).

**Conclusion** Patients with CKD in rural areas face profound and inequitable challenges of displacement, financial burden and separation from family in accessing KRT, which can have severe consequences on their well-being and outcomes. Strategies are needed to improve access and reduce the burden of obtaining appropriate KRT in rural communities.

## INTRODUCTION

Patients with chronic kidney disease (CKD) from rural communities have a higher risk of mortality, morbidity, hospitalisation and worse quality of life compared with patients with CKD in urban areas.<sup>1,2</sup> This likely reflects barriers in accessing healthcare. Patients with CKD residing outside of urban areas are less likely to access nephrology services and to

## Strengths and limitations of this study

- We conducted a comprehensive search and followed a systematic and transparent approach to synthesise the findings from the primary studies.
- Investigator triangulation ensured that the full range and depth of data from the primary studies were captured and reflected in the synthesis output.
- Non-English articles were excluded.
- The majority of studies were from high-income, English-speaking countries, which may limit the transferability of the findings. Many of the studies were conducted in Australia and New Zealand.
- The term 'rural' was not consistently defined across the articles.

receive the recommended testing, treatment and education about CKD including options for kidney replacement therapy (KRT).<sup>3-5</sup>

Barriers to access include the burden of travelling long distances to clinical appointments and costs of accommodation.<sup>6</sup> Patients from a rural area may not be able to access their preferred option of KRT. For example, patients may not be able to do home haemodialysis because of the lack of training available in rural facilities or environmental factors such as limited access to sufficient and clean water.<sup>1,7,8</sup> Also, they may also be less likely to be waitlisted for transplantation and take longer to be placed on the list due to difficulties in accessing screening tests and nephrologist appointments as required.<sup>9,10</sup>

Synthesising evidence from multiple qualitative studies on patients' perspectives on access to KRT can generate new and comprehensive insights across geographical settings and populations. This study aims to describe the perspectives of patients and caregivers on access to KRT 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 Enhancing Transparency of Reporting the Synthesis of Qualitative Research framework.<sup>11</sup>

### Selection criteria

Qualitative studies that described the experiences and perspectives of adult patients with CKD and caregivers (aged over 18 years) residing in a rural location, on access to KRT (dialysis or transplantation) in any geographical area were eligible. We included all types of KRT to obtain a broad diversity of patients' perspectives, and to understand the range of different barriers and challenges in accessing the different forms of KRT. We included all studies in which the authors have explicitly stated that patients in the original study were from areas<sup>12</sup> and there were no restrictions based on date of publication. The definition and scope of access for this paper is based on the WHO definition, which included the opportunity to reach and obtain appropriate healthcare services in situations of perceived need for care and 'includes the right to seek, receive and impart information and ideas concerning health issues'.<sup>13</sup> Non-English studies were excluded to avoid misinterpretation of linguistic and cultural nuances in translation.

### Data, sources and searches

The search strategy is provided in online supplemental table 1. Searches were conducted in Medline, Embase, PsycINFO and Cumulative Index to Nursing and Allied Health Literature from database inception to 17 March 2019. Reference lists of included articles were also searched. Two authors (NJS-R and AT) independently screened the titles and abstracts of the search results and excluded those that did not meet the inclusion criteria. The full texts of potentially relevant articles were assessed for eligibility. Online supplemental table 2 contains characteristics of all included studies.

### Data extraction and quality assessment

All texts under the sections Results/Conclusions from included studies were extracted electronically and entered into HyperRESEARCH V.3.7.3 (ResearchWare). The comprehensiveness of reporting of each qualitative study was independently assessed by four authors (NJS-R, AB, DJT or VS) using the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) framework, which includes items specific to research team, study methods, study context, and method of analysis and interpretations.<sup>14</sup> We resolved any discrepancies in the assessment of the COREQ by discussion.

### Data analysis

We used thematic synthesis to analyse the data.<sup>15</sup> All participants' quotations and texts under the Results/findings or Discussion/conclusion section from the included

studies were entered into the software HyperRESEARCH V.3.7.3 for data management. The first author conducted line-by-line coding of each study and inductively identified concepts on access to KRT. Similar concepts were grouped into themes and subthemes. Five authors (NJS-R, AB, DJT, VS, and AT) also read the papers, and reviewed and discussed the preliminary analysis to ensure that the full range and depth of data were included in the analysis. The first author developed a thematic schema to indicate conceptual patterns and links among themes, which was refined based on discussion with the investigators.

### Patient and public involvement

First author NJS-R has lived experience of both dialysis and kidney transplantation and resides in a rural community. NJS-R conceived the idea for this study, conducted the searches, screening, data collection and analysis, and drafted the manuscript.

## RESULTS

### Literature search and study description

Our search yielded 2493 articles, of which 18 articles involving 540 patients and carers from 8 countries (Australia, Canada, the UK, New Zealand, Ghana, the USA, Tanzania and India ([figure 1](#))) fulfilled the eligibility criteria and were able to be included. Data were collected using interviews and focus groups. Nine studies were conducted in rural Indigenous or First Nations communities. The study characteristics are provided in [table 1](#).

### Comprehensiveness of reporting

Studies reported on 2–18 items in the adapted 26-item COREQ framework (online supplemental table 2), this may allow readers to assess the rigour of the studies. The participant selection strategy was described in all studies. Audio-taping and transcription was stated in 16 (89%) studies. Investigator triangulation was reported in 12 (67%) studies. Participants' quotations to support the findings were available in 16 (89 %) studies.

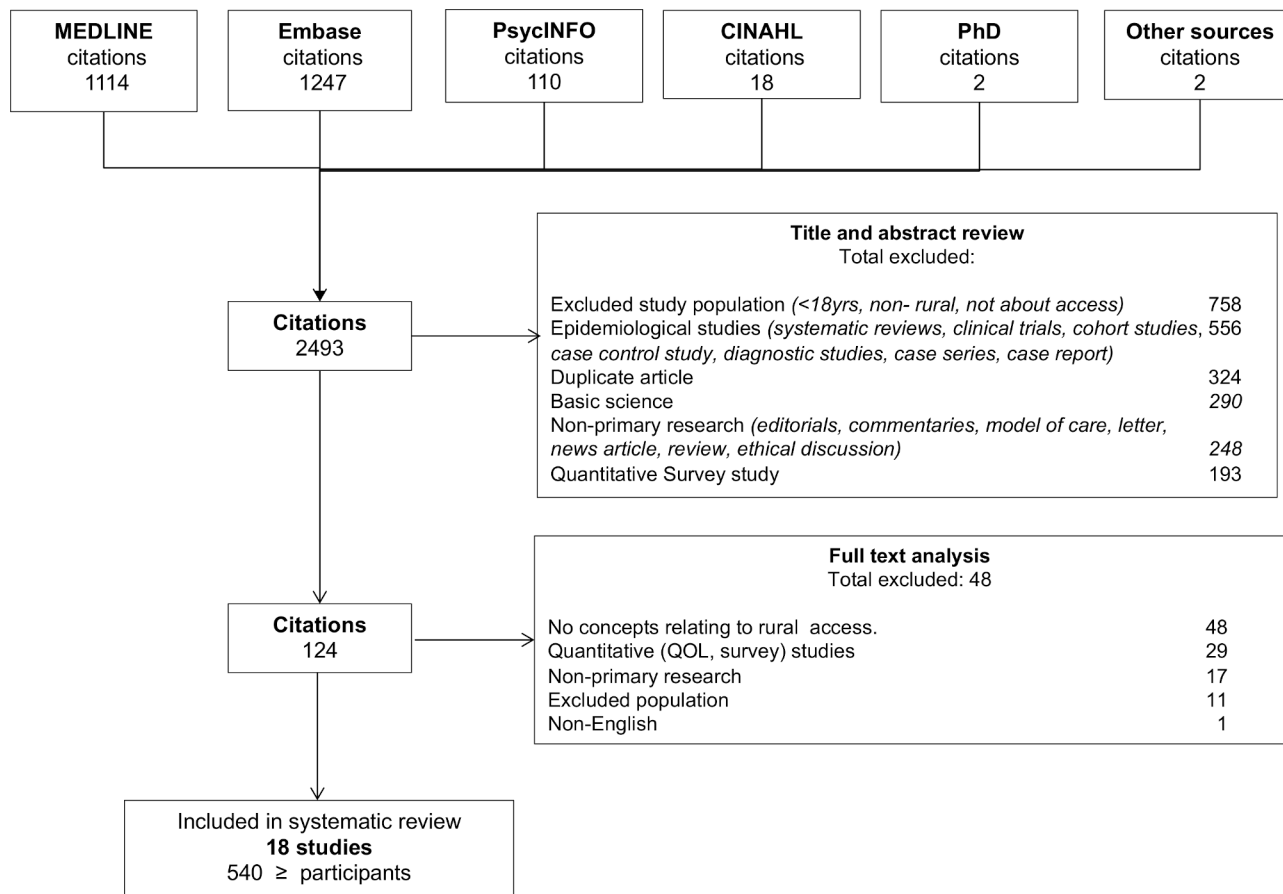
### Synthesis

Five major themes and respective themes were identified, and are described below with selected participants' quotations to illustrate each theme are provided in [table 2](#). An analytical schema depicting the relationships among the themes is shown in [figure 2](#).

### Uncertainty in navigating healthcare services

#### Struggling to absorb information

Participants nearing commencement of KRT felt they were given too much information by their doctors and nurses within a short period of time. They were unable to process or retain the verbal information as "you're just freaking out".<sup>16</sup> Patients found that the written information contained "all the medical jargon and abbreviations",<sup>16</sup> which made it difficult to make informed decisions about their care. Indigenous patients and caregivers in Canada, involved in the design of an information



**Figure 1** Search results. CINAHL, Cumulative Index to Nursing and Allied Health Literature; QOL, quality of life.

pack for remote communities, emphasised the need to use language “that was understandable by people not familiar with medical terms”.<sup>17</sup>

#### Without familiarity and exposure to options

Participants “didn’t know what to expect [with dialysis or transplantation], nobody told me”.<sup>18</sup> As such, commencement of dialysis was the “biggest shock” of their lives.<sup>18</sup> They were confused about the choices available, particularly the option of transplantation—“[we] don’t know anything about it, or how people get on the list”.<sup>19</sup> Patients struggled to decide between peritoneal dialysis or haemodialysis because they had “actually never seen the bag be done, I’ve only ever seen the machine once at hospital”.<sup>16</sup>

#### Yearning for cultural safety

Studies conducted in communities that included First Nations people emphasised that clinicians needed to understand the importance of culture<sup>16</sup> and “know what it’s like for you, what’s important”.<sup>16</sup> Some perceived that clinicians were culturally unaware and “don’t know whether its culturally appropriate to even ask”<sup>7</sup> certain questions, including about transplantation. Having treatment options close to home was important to First Nations patients so they could pass on health information to the younger generations—“to look after yourself, or else you end up like me, stuck to the chair”.<sup>20</sup> Australian indigenous patients believed that they would “learn a lot

better” about kidney disease and treatment choices if it was provided by people from their own culture.<sup>21</sup>

#### Lacking trust in clinicians

Patients found it difficult to make decisions about treatment if they thought their clinicians were withholding or reluctant to share information—“[they] don’t give it [information] the right way. Instead of like trying to teach them [patients], they [doctors] come across like they know everything and they don’t compromise on that, hey? When they come across like that everyone’s too scared to ask them questions why, so then they just shut up and think, Well I’ve been told this, so that must be it”.<sup>7</sup> Patients in rural villages in Ghana reported being told by doctors that “when we are going to treat you it will cost you much money so it’s better, the money that you will use for the treatment, it’s better you go home and then use the money to look after your children”.<sup>22</sup> This, they believed showed that the doctors had already made up their minds about what treatment they should get and did not discuss it with the patients and their families.

#### Intense burden of travel and cost

##### Poverty of time

Caregivers who supported their family members with kidney disease felt “disturbed by the need of travelling every week for dialysis and the long dialysis procedure,” and for some this travel burden caused them to feel

**Table 1** Comprehensiveness of reporting in included studies

Item	Studies reporting each item (references)	Number of studies
<b>Personal characteristics</b>		
Interviewer/facilitator identified	7 16–19 21 23 25 28 29 31–33	15
Occupation of the interviewee of facilitator	16 18 19 22 25 29 31	8
Experience or training in qualitative research	16 18 19 22 23 25 29 31	7
<b>Relationship with participants</b>		
Relationship established prior to study commencement	16 18–20 25 29 30	7
<b>Theoretical framework</b>		
Methodology	7 16–21 23–26 28–33	18
<b>Participant selection</b>		
Sampling strategy	7 16–21 23–26 28–33	18
Method of approach or recruitment	7 16–25 29–32	15
Sample size	7 16–21 23–26 28–33	18
Number and/or reasons for non-participation	7 18 19 21 22	5
<b>Setting</b>		
Setting of data collection	7 16–21 23–25 28–33	17
Presence of non-participants (eg, clinical staff)	19 22	2
Description of the sample	7 16–21 23–26 28–33	16
<b>Data collection</b>		
Questions, prompts or topic guide	7 16–21 23–26 28–33	18
Repeat interviews/observations	17 22 31	3
Audio/visual recording	7 16–21 24–26 29–33	16
Field notes	16–18 20 23 29	6
Duration of data collection (interview or focus group)	7 17–20 22 23 25 26 28 29	10
Data (or theoretical) saturation	16 17 19 20 22 23 25 29 30	8
Language of data collection	7 16 17 19 20 22 23 25 29 30 33	11
<b>Data analysis</b>		
Researcher/expert triangulation (multiple researchers involved in coding and analysis)	7 16 18–22 25 31–33	12
Description of coding framework/tree	7 16–21 23–26 29–33	17
Derivation of themes or findings (eg, inductive, constant comparison)	7 16–21 23–26 29–33	17
Use of software (eg, NVivo, HyperRESEARCH, Atlas.ti)	7 16 18–22 25 26 29 30 33	12
Member checking (participant feedback on findings)	16–21 24–26 29 31	11
<b>Reporting</b>		
Participants' quotations or raw data provided (picture, diary entries)	7 16–21 23 25 26 28–31 33	16
Range and depth of insight into access to KRT for rural patients and their caregivers (>25% of themes)	7 16–21 23 25 26 28–31 33	17

KRT, kidney replacement therapy.

exhausted and unwell—“[I am]so tired of the care of my brother that I feel like I am ill myself”.<sup>23</sup> Patients who lived a long distance from their dialysis centre reported that they could be away from home for in excess of 12 hours on haemodialysis days because of travel, and this had a detrimental impact on the quality of their non-dialysis days due to fatigue from travel and treatment.<sup>24</sup> In the study conducted in Ghana, rural patients who were working could not travel to dialysis because they could not take time off—“three days off? No, it's not possible”.<sup>22</sup>

#### Exposure to risks and hazards

With patients and caregivers being required to travel long distances to access care, this meant they were exposed to risks related to adverse weather, vehicle accidents (including with animals) and stress from travelling on the highways, particularly if they were travelling after dark.<sup>24</sup> In a study conducted in India, travelling from remote villages to dialysis, often at night after dialysis sessions, was particularly exhausting because the roads

**Table 2** Illustrative quotations

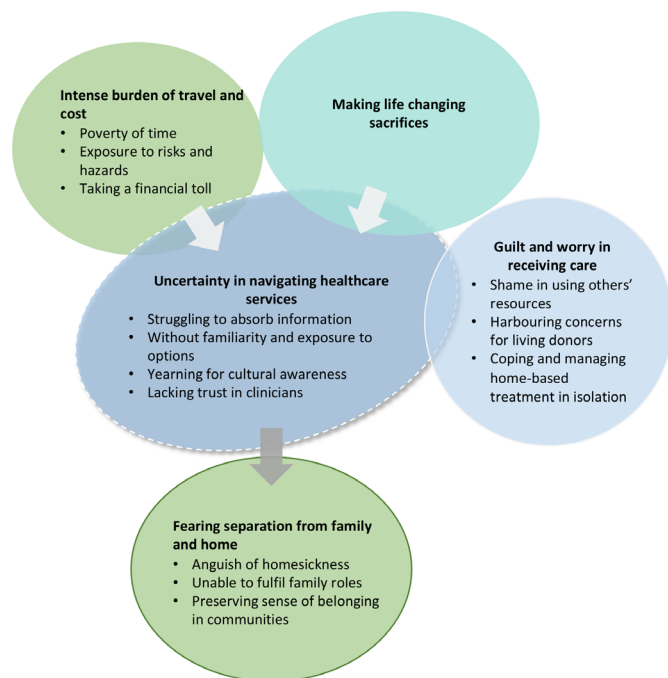
Theme	Quotations	Sources
Uncertainty in navigating healthcare services		
Struggling to absorb information	<p>But that time of first meetings with the specialists, with renal nurses, they was explaining a lot of things...which actually just went in one ear and out the other, because you're just still going through the initial shock.<sup>21</sup></p> <p>"The education is low ... I was here [renal center] for almost two years but I didn't have any idea about what is affecting me ... .and there is some secrecy surrounding the whole thing<sup>22</sup></p> <p>"I didn't know it was going to take a long time like this...yeah, I felt within 6 months I have to be cured"<sup>22</sup></p>	16–18 20 22 27 32
Without familiarity and exposure to options	<p>Lack of information on living kidney donation: It's a major thing 'cos don't know nothing about the operation...nobody said nothing<sup>7</sup></p> <p>'I have not even thought about that [home HD]. And yet I've seen people coming through the corridor to do the home training unit. No, I've never even been told'.<sup>16</sup></p> <p>I don't really remember her educating me about it at all, I really don't think you do get enough information<sup>16</sup></p>	7 16–18 31
Yearning for cultural safety	<p>"a life that has meaning in their terms"<sup>33</sup></p> <p>Yeah that's what I'm scared of, but her transplant was from - not from her family- [it was] from a white person - I don't know<sup>7</sup></p> <p>But the majority of our people are very shy, they frightened to ask questions of anybody, specially a white person and that's why they find they got a few problems, because they frightened to ask for some advice"<sup>18</sup></p>	7 16 18–20 29 33
Lacking trust in clinicians	<p>'There are some people I can't talk to. I had this bad time with my doctor, and I just walked out, he just didn't know how to talk to me and so I just said nothing and said I had to go'.<sup>16</sup></p> <p>If the doctor had explained to me that I was going onto the kidney machine I would have by all means understood. He talked with the other doctors and I could hear him saying something about kidney failure, but they never once told me that I was getting on the kidney machine.<sup>18</sup></p> <p>we would like to be spoken to clearly in an understandable way by doctors... by doctors who like Anangu (Aboriginal people), by understanding [empathetic] doctors who talk - they're good—a lot of other doctors can't talk with us...their talk is hard [to understand].<sup>7</sup></p>	7 16–18 22
Intense burden of travel and cost		
Poverty of time	<p>Patients talked about being away from home for 12 hours or more on the day that they were travelling to the hospital HD unit, and that often impacted negatively on the length of their recovery time from dialysis sessions.<sup>24</sup></p> <p>"Since I'm working I can't have that time coming three times in a week, from [Eastern Region] to this place [Greater Accra Region].<sup>24</sup></p> <p>"We feel much disturbed by the need of traveling every week for dialysis and the long dialysis procedure is seriously troubling my father."<sup>23</sup></p>	15 21–25
Exposure to risks and hazards	<p>Safety, time and cost all contributed to this burden. All seven patients reported travelling in adverse weather conditions with one patient reporting a 7.5-hour drive in what would normally be a 2.5-hour drive, because of a winter storm.<sup>24</sup></p> <p>One of the unique concerns for patients travelling long distances in Canada is the abundance of moose on the highway....all patients reported having close calls or "narrow escapes" with moose.<sup>24*</sup></p> <p>As well, all patients reported an increased level of stress related to their safety on the highway, especially after dark. Patients reported long and hazardous trips to reach HD services prior to the satellite services.<sup>24</sup></p>	23 24
Taking a financial toll	<p>"We can't find any money for our daughter's college fees and other needs as all our money goes into the treatment of my husband and I am also not able to go for work as I need to accompany him."<sup>23</sup></p> <p>Travelling every week from our village to this hospital is costly and we have to change 3 buses, which causes many difficulties to patient and frequent expenses."<sup>23</sup></p> <p>"...there are also family financial problems which can prevent a person from getting these [dialysis] treatments...you also have to pay for lab tests"<sup>30</sup></p>	18 22–25 30
Fearing separation from family and country		

Continued

Table 2 Continued

Theme	Quotations	Sources
Devastating homesickness	<p>"I was born [there] ...It sort of broke my heart, leaving all my family up there ... My boyfriend is there and my grandchildren and my daughter. It's a long time now ...I can explain it this way: it is my home, my land, my customs when I go up there".<sup>28</sup></p> <p>"I can't go [home] and I'm really missing my friends and my family...I'm getting used to living in town now - but in my spirit I really want to be able to go home..."<sup>7</sup>.</p> <p>*Despite the risks of missing hemo-dialysis, one patient explained how he often misses treatments to travel to his Country to take part in local meetings<sup>20</sup></p>	7 20 28
Unable to fulfil family roles	<p>"Dialysis changes our life, just like that you know. Yeah, we can't even do things and can't go anywhere...used to go out every day, go away to get work. Now can't even push the mower, it messes the fistula up."<sup>20</sup></p> <p>"I miss out on hunting Kangaroo, showing kids the Country, teaching our children about our dreaming".<sup>20</sup></p> <p>'Moving away from family is important, we've got family at home that rely on us a lot with the grandchildren and we lose that too and we're letting them down'<sup>16</sup></p>	16 18 20 22
Preserving a sense of belonging in community	<p>'We go to a lot of hui (meetings), to the marae (cultural meeting house). That was a lot of the reason why I wanted to go home too. I can work around it. I don't have to miss it'.<sup>25</sup></p> <p>When considering choice of dialysis treatment, many spoke of making decisions to enable them to continue in their roles within the family and community, as this was seen as an important aspect of their personal and cultural identity.<sup>25</sup></p>	17 20 25
Managing life-changing consequences		
	<p>I am always worried over the fact that my wife is suffering from a disease which has no cure and that she may die eventually"<sup>23</sup></p> <p>'I got two aunties in Adelaide and they been renal for 20 years. They like to come back to visit Coober Pedy but they got no accommodation. So, they can't go, they gonna stay in a hotel? They are trying to raise that issue but nobody listens to us'.<sup>20</sup></p> <p>"I am finding difficulty in getting an alliance for marriage as I am burdened with father's care and people shy away from my marriage proposals" and a woman complained that, "My neighbors and relatives don't come to us anymore"<sup>23</sup> if you have land or livestock you are forced to sell for your patient to receive treatment. People sell even their houses; they don't sell them for pleasure<sup>30</sup></p>	16 20 23 24 30
Grief, guilt and worry in receiving care		
Shame in using others' resources	<p>We feel shame because it is not our Country here. What is someone else is from here and they can't come back from Adelaide coz there's not chairs here. I've taken up that chair. [We] feel a lot of shame for that"<sup>20</sup></p> <p>They felt they had displaced others from a dialysis position in their home town by occupying a dialysis chair that might otherwise been used by a local member starting dialysis.<sup>20</sup></p>	19 20
Harbouring concerns for living donor	<p>I had a mate in [country] who said 'I'll give you one'...but his problem would have been financial. He's got a no contract job, he lives from hand to mouth, I know that they can help after the operation if you can't work but just taking the days off for the tests would have, you know, put him under the—so I was very dubious about asking him cos officially I'm not allowed to give him any money.<sup>19</sup></p> <p>'When my wife offered to give me her kidney, it's not that you're ungrateful but I didn't want her to go through that for me."<sup>31</sup></p>	7 18 19 27 30 31
Coping and managing home-based treatments in isolation	<p>'I just felt I didn't have the confidence to be doing it at home alone, I thought if something went wrong, I did something wrong I'd panic terribly'.<sup>25</sup> I'm fine to do the dialysis at home, if they offered someone to come in and put the needles in and then take them out maybe, although maybe with time I'd get better and be able to take them out, that is the only thing stopping me from going home'.<sup>16</sup></p> <p>"She's not really keen to do it. I'm wanting to do it, but she's a bit frightened that something might go wrong and she don't wanna do it and take responsibility".<sup>18</sup></p>	16 18 25

\*Not a quote but summary of patients' or caregivers' comments.  
HD, high dependency.



**Figure 2** Thematic schema for patients and caregivers from rural communities, access to kidney replacement therapy initially involves an intense burden of travel and cost and making life-changing sacrifices. Once they are able to reach the appropriate services, there can be uncertainty in navigating those services and also guilt and worry in receiving of the care. To continue to access this life-saving therapy often means separation from family and their homes.

and hazardous conditions were not always conducive to a restful journey.<sup>23</sup>

#### Taking a financial toll

Some patients were unable to choose home-based treatment options as they were “afraid of the machine using lots of power...worrying it would be too expensive to run it”.<sup>25</sup> We can’t find any money for our daughter’s college fees and other needs as all our money goes into the treatment of my husband and I am also not able to go for work as I need to accompany him.”<sup>23</sup> Patients stated that “a huge barrier” to living donor kidney transplantation was the expense of relocating to be close to a transplant unit for “3 months,” which for some patients meant their caregiver would have to “quit [their] job”.<sup>26</sup>

#### Fearing separation from family and home

##### Anguish of homesickness

For patients from remote Australian Indigenous communities, confronting the need for dialysis meant being “taken away from your own Country (Country is used in this context to mean a connection to the land that is culturally significant to the indigenous people of Australia), Country is family, culture, identity... is self.”<sup>27</sup> Their “spirit wants to get back to your own Country” and it would be unbearable to “get homesick”.<sup>28</sup> For this reason, these patients preferred a transplant. They emphasised that being away from<sup>7</sup> friends and family would cause extreme “suffering”,

and some indicated they would be willing to miss treatments to be able to travel back to their “Country”,<sup>20</sup> and would “want to run away” to go back home to die. In Canada, Indigenous patients and their families who had to relocate to receive treatment were concerned about the poor quality of housing that was provided in the urban centres, including overcrowding where “they had to put four of us in the room”, and lack of disability access, and patients were “asked to move from room to room”.<sup>29</sup>

#### Unable to fulfil family roles

Indigenous patients from remote communities, who had to move on to “the wrong Country” for dialysis, were distressed about being unable to teach their grandchildren about “hunting”, “dreaming” and “showing kids the Country”.<sup>28</sup> Having to move away for dialysis caused patients to feel they were “letting them [families] down”.<sup>25</sup> They felt that their illness changed the roles in their families and that they did not want their children “stuck here and looking after” them all the time.

#### Preserving sense of belonging in community

First Nations people of New Zealand opted for the treatment modality that would allow them the freedom of “being able to attend hui [meetings] and tangi [funerals] and unveilings... as that is what makes us”.<sup>25</sup> They made decisions that would best allow them to continue with their roles in the community and family, to protect their sense of belonging.<sup>25</sup> Indigenous patients who had the option of returning to Country for short periods of time with mobile dialysis felt “they were transformed”, and that it improved the social and emotional well-being for them and also their families.<sup>20</sup>

#### Making life-changing sacrifices

For patients from a rural area on dialysis, the locations of haemodialysis units involved “a lot of travelling” and relocation, which meant they had to make major sacrifices in their way of living.<sup>16 18</sup> For some caregivers, their partner had to relocate for treatment and the separation was agonising—“almost like half my life was gone”.<sup>29</sup> Some patients who moved to receive dialysis treatment, they were unable to return home because transport was not available to allow them to visit family and Country—“they like to come back to visit...but they got no accommodation,”<sup>20</sup> so they could not go home. Some patients from rural areas who wanted home-based therapies, had to “move to [a city] to learn for 3 months,” which they regarded as “really not fair.”<sup>25</sup> Patients and their families in countries in which they could not access insurance or universal healthcare cover explained they had to sell property to access care—“if you have land or livestock you are forced to sell for your patient to receive treatment. People sell even their houses; they don’t sell them for pleasure”.<sup>30</sup>

#### Guilt and worry in receiving care

##### Shame in taking resources from others

Patients felt guilt in using medical resources in other regions—“[I] feel shame because it is not our Country

here...we have taken someone else's [dialysis] chair".<sup>20</sup> They believed they were depriving others, for example a local person who may need access to a dialysis chair in their local hospital.<sup>20</sup>

#### Harbouring concerns for living donor

For patients considering living kidney donor transplantation, they expressed concern for the safety of the donor who was often their caregiver as well. They did not want their family member to go through the surgery and trauma on their behalf.<sup>31</sup> The distance required to travel to and from the transplant unit for donor and recipient, who were living a distance from the transplant centre, was seen as an impediment by patients.<sup>32</sup> Some patients were concerned that their potential donors would have to "have a day off" to travel to the transplant centre, which they were not prepared for them to do.<sup>19</sup> Some were confused about where the donor testing had to be conducted, and if potential donors could access reimbursement for pre-transplant testing.<sup>32</sup>

#### Coping and managing with home-based treatment in isolation

When patients from a rural community were initially faced with the option of home dialysis, it "seemed a little scary but more convenient" especially for those who lived some distance from their closest hospital.<sup>25</sup> They were a "bit frightened that something might go wrong" and that it was a lot of "responsibility".<sup>18</sup> It felt that it would "be helpful to have a support person" to provide reassurance or medical assistance, which would make them more willing to try home haemodialysis as they felt they had a "safety blanket".<sup>25</sup>

## DISCUSSION

Patients with CKD who live in rural areas face profound challenges and barriers in accessing KRT. The burden of travel and cost, being vulnerable to travel-related risks, and the need to make major sacrifices made it difficult to access care. Patients felt daunted in trying to understand and navigate healthcare services because it was difficult to process the information, they had little exposure to the options for KRT, were concerned about cultural safety and some were unable to trust clinicians. They felt they were burdening their families and harboured guilt because they believed that they were taking resources from local patients if they dialysed outside of their community. They also feared being separated from their families, home and their communities, and were therefore reluctant to access treatment far away.

Of note, over half of the studies in our review were conducted in First Nations peoples, specifically indigenous Australians and Canadians and First Nations Maori people in New Zealand. A barrier to accessing KRT specific to these populations included delivery of culturally insensitive communication. These barriers may also relate to cultural values including the need to be connected to Country, which was 'family, culture,

identity' and having to relocate away from Country for treatment had a devastating impact beyond separation from home and family, and was a reason patients gave for choosing not to access KRT at all. Particularly in Australia and Canada, Indigenous patients living in rural locations had to relocate long distances from their homes to receive KRT, in many cases requiring more than a day's travel.<sup>7 17 18 20 28 29 33</sup>

There were some differences based on healthcare systems across countries. For patients without access to universal healthcare and living in low-income to middle-income areas (for example, in Ghana, Tanzania, India), financial barriers were a major concern. Economic barriers identified included the cost of transportation, accommodation and out-of-pocket expenditure, and some patients were unable to afford any treatment, most notably those who were uninsured and in countries without universal health coverage.<sup>13 23 34-36</sup> The majority of studies conducted in Australia and New Zealand were focused on indigenous patients, and this may be because a higher proportion of indigenous patients resides in rural and remote locations. There were priorities, concerns and needs related to access that were unique to these communities. For example, the subtheme of yearning for cultural safety. Both Australia and New Zealand have a publicly funded healthcare system, and those with private health insurance may access health service providers that are owned and managed privately.

We recognise that the challenges in accessing healthcare among patients from a rural area with CKD may also be experienced by patients in urban areas. The financial burden arising from transportation costs and perceived lack of education regarding their kidney disease and treatment options, have also been identified as barriers by patients residing in urban communities.<sup>37 38</sup> However, our findings highlight concerns and problems that are likely to be unique in rural settings, including the additional costs of travelling longer distances and accommodation for months at a time, and the environmental hazards and risks of living in remote areas. Also, the extended periods of separation from their family and communities impacted their sense of belonging and exacerbated isolation and loneliness, leading to concerns about the sustainability of treatment.

The disadvantages and disparities in access to care have also been expressed by patients in rural and remote areas with other chronic conditions. The burden of travel has been identified by patients with cardiovascular disease and cancer.<sup>39-41</sup> In a study among rural patients with cancer on accessing healthcare, they emphasised the burden of travel, accommodation costs, financial burden and the need to relocate to access treatment as major barriers. These impacted their relationships with family, increased their psychological stress and sense of social isolation during treatment and added the burden of fatigue from the physical strain of travel and living away from home.<sup>39</sup>



In this study, we conducted a comprehensive search and independent assessment of study reporting. We involved multiple researchers in the analytical process (investigator triangulation), to ensure that all data from the primary studies were reflected in the final analysis. However, there are some potential limitations. Non-English studies were excluded to avoid misinterpretation of linguistic and cultural nuances in translation, and the majority of studies were from high-income, English-speaking countries, which may limit the transferability of the findings. Many of the studies were conducted in Australia and New Zealand. We acknowledge the potential ambiguity in our inclusion criteria because the term ‘rural’ was not consistently defined across the included studies. Our synthesis was limited to the data reported in the primary studies because we could not access the full data set for ethical reasons.

Our findings show that for patients with CKD in rural areas, access to KRT is very difficult to navigate. Patient navigator programmes, eHealth, and strategies to facilitate and encourage home dialysis are suggested to address some of these barriers. Patient navigator programmes are being increasingly implemented, with evidence that they may help to improve processes of care and potential disparities in access associated with low socioeconomic status or cultural and linguistic diversity.<sup>42–45</sup> Telehealth or eHealth has been shown to benefit rural patients and their caregivers in other chronic diseases as well as various stages of CKD, with regard to management and provision of education, and have helped to reduce the burden of travel and cost on these patients.<sup>46–50</sup>

Interventions that improve uptake of home-based therapies are suggested to minimise travel and the need for patients to relocate away from community and home.<sup>51 52</sup> However, as shown in this review, there is some reticence for patients to commence this, often because of lack of exposure to, and education about these options. This could be addressed through a more graduated programme of education whereby patients are provided options for treatment and able to see them first hand, or through patient navigators who can provide reassurance from a patient’s perspective to assist with alleviating some of the concerns.<sup>53</sup> Perceptions of increased out-of-pocket costs together with unsuitable housing, often limit the patients’ choices of these modalities.<sup>54</sup> To improve access to home dialysis, policy and programme would need to address these financial issues to assist patients to minimise costs.<sup>54 55</sup>

There is a need for evidence to improve access to care for patients with CKD in rural areas, particularly in terms of addressing the financial and travel burden, education, and availability of different treatment options in rural and remote locations. We suggest that further work to evaluate the financial burden and out-of-pocket expenditure for rural and remote patients and their families may inform policy and service provision.<sup>56 57</sup> Funding and service delivery

models differ across healthcare jurisdictions, which would need to be taken into account in formulating strategies to address financial barriers.<sup>58</sup> Evaluation of education that is provided to patients would benefit from a review and appraisal of alternate ways for this to occur so that patients receive culturally appropriate education in a way that allows them to understand and evaluate all options for KRT and does not add to their travel burden. Availability and evaluation of existing alternate models of service delivery for rural and remote patients, such as the Purple House in Australia,<sup>59</sup> community-based dialysis houses in New Zealand and use of telehealth worldwide, is required to maximise the availability and minimisation of cost for patients to access treatment.<sup>60</sup>

Patients with CKD living in rural areas face displacement, financial burden and separation from family in accessing KRT. This can have severe consequences on their well-being, perceived safety, satisfaction with care and health outcomes. Strategies are needed to improve access and reduce the burden associated with accessing KRT in rural communities, globally.

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