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Health professional experiences of kidney transplantation in regional, rural, and remote Australia

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Abstract

Background Despite the demonstrated improved patient survival and financial benefits for health services with kidney transplantation compared to dialysis, populations outside of urban areas face inequities in access and a more difficult journey to kidney transplantation than their metropolitan counterparts. This study aimed to explore the experiences of Australian kidney transplant health professionals regarding kidney transplantation processes for patients residing in regional, rural, and remote areas, with a focus on improving access to and experiences of transplantation for this patient cohort.

Methods Semi-structured interviews were conducted with Australian kidney transplant health professionals. Transcripts were analysed thematically.

Results Interview participants ($n=26$) consisted primarily of nephrologists from transplanting centres (15%), nephrologists from regional, rural, or remote non-transplanting centres (19%), clinical pharmacists (19%), and nursing staff (19%). Six main themes were identified regarding barriers to transplantation, including ineffective communication and education, overwhelming geographical burden, fighting for equal opportunities, paucity of social support, crushing financial peril, and deprived of adequate local care. Participants also made recommendations for new or modified service delivery models to address identified barriers, including coordination of work-up testing, outreach visits for transplant assessment, increased social and financial support, and increased and earlier provision of transplant education.

Conclusions Health professionals described patient-specific and system level barriers to kidney transplantation for regional, rural, and remote populations in Australia that could be addressed or improved by the modification of current processes or implementation of new service delivery models for provision of transplant care.

Keywords Rural and remote health, Chronic kidney disease, Kidney failure, Kidney transplant, Indigenous health, Health equity

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Background

It is estimated that 45% of the total global population resides outside of urban areas [1], with approximately 29% of the Australian population living in regional, rural, or remote areas [2]. The estimated global prevalence of chronic kidney disease (CKD) is >10% [3, 4], and rural and remote populations worldwide have much higher rates of CKD, kidney failure (KF), and associated mortality compared to those in metropolitan cities [5–7].

The cost of dialysis as a kidney replacement therapy (KRT) modality presents an increasing health resourcing burden, with the average annual cost of in-centre haemodialysis in Australia ranging from AUD\$85,000–AUD\$124,000 per patient depending on dialysis facility geographical remoteness [8]. Alternatively, kidney transplantation offers significant financial benefits for health care systems [9] as well as improved quality of life and overall survival rates for patients, when compared to dialysis [10]. Lack of access to kidney transplantation therefore has significant implications. Whilst preemptive kidney transplantation is being increasingly used in countries across Europe as a way to reduce delays to transplant, avoid dialysis and achieve improved transplant outcomes [11], KF patients in Australia must have commenced on dialysis in order to be eligible to receive a deceased donor transplant [12].

Regional, rural, and remote patients across the world are less likely to be waitlisted for or receive a kidney transplant, despite the increased burden of CKD and KF [13–15]. Indigenous populations are also far less likely to receive a kidney transplant [16], a disadvantage that is further exacerbated by residing in rural or remote areas [17]. For those who do receive a kidney transplant, they usually spend longer on dialysis prior to waitlist activation [18], which is associated with worse long-term outcomes and overall survival post-transplant [19].

In Australia, the delivery of specialist kidney transplant services occurs via a hub-and-spoke model, with almost all current transplant units based in metropolitan hospitals [12]. With regards to potential or actual kidney transplant recipients from regional, rural, or remote areas, provision of care is therefore a shared responsibility between the transplanting centre and the home nephrology service. The kidney transplant centre reviews the patient with regards to determining their eligibility for transplantation, as well as providing care in the peri- and acute post-transplant period, whereas the regional, rural, or remote home nephrology service facilitate the work-up process and provide care pre-transplantation as well as the long term care post-transplant care [12].

For patients residing in regional, rural, and remote areas, many additional barriers to kidney transplantation have been identified, largely associated with the need to travel or relocate temporarily in order to access medical

testing and transplantation facilities [20]. Previous studies looking at barriers to transplantation for rural and remote populations globally from the perspectives of health professionals, have focused on Indigenous populations specifically [21, 22], explored the perspectives of only nephrologists [23–25], or have investigated access to all forms of KRT [26].

The objective of this study was to explore the experiences of Australian kidney transplant health professionals regarding kidney transplantation processes for all patients residing outside of metropolitan areas. The focus was understanding the current barriers to kidney transplantation and identifying ways in which access to, and experiences and outcomes of kidney transplantation could be improved for patients in Australian regional, rural, and remote areas.

Methods

Study design and participant selection

One-on-one semi-structured interviews were conducted with a multidisciplinary cross section of kidney transplant health professionals including nephrologists, transplant nurses, clinical pharmacists, and other allied health or support staff. Health professionals based in kidney transplantation units, as well as regional, rural, or remote healthcare facilities providing pre- and post-transplant care within Australia were eligible. Geographical remoteness of participants was defined according to the Modified Monash Model (MMM) 2019 using principle place of practice location [27]. Sampling was via a purposive non-probability method to ensure the research objective was answered, and participants were selected for recruitment by the investigators to ensure a sample that was representative of the transplant health professional population. Given the provision of care to regional, rural, and remote kidney transplant units is shared, the investigators felt it was necessary to include participants from both the metropolitan based transplanting centres, as well as those from the regional, rural, or remote home nephrology services. However, to ensure that participants were able to adequately answer the research objective they were only eligible to participate if they had direct involvement in the provision of care to regional, rural, and remote kidney transplant recipients specifically. Written consent was obtained from all participants and verbally reconfirmed prior to commencing their interview. Further information regarding recruitment can be found in Supplementary Material 1. Multisite ethics approval was granted by the Townsville Hospital and Health Service Human Research Ethics Committee (HREC/2023/QTHS/89342). This study was reported following the Standards for Reporting Qualitative Research (SRQR) [28].

Data collection

A semi-structured interview guide was developed based on findings of a scoping review [20]. The interview guide (Supplementary Material 2) was reviewed and discussed with all members of the research team and two pilot interviews were conducted to ensure content clarity and value of response data in addressing the research objective. These interviews were undertaken by the principal investigator using online videoconference platform Microsoft Teams (MS Teams, Version 24231.507.3099.9636, Microsoft, Redmond United States) which also recorded and transcribed the interviews verbatim. Transcription records were manually checked against the recordings by the principal investigator to ensure accuracy. Data collection ceased once data saturation was achieved, with no new themes identified. A total of 26 interviews were conducted over a 3-month period from April to June 2024 and all participants were provided with a \$20 gift voucher to compensate them for their time.

Data analysis

Interview transcripts were analysed using a descriptive thematic method following the Braun and Clarke framework [29, 30]. Data were imported into NVivo (NVivo,

Version 12, Lumivero, Denver United States), and both inductive and deductive coding used to identify the relevant and recurrent themes and develop associated theories. Initial deductive codes used were obtained from the findings of the scoping review [20], and then further developed during the iterative analysis process. Review and coding of the data was carried out by the principal investigator, with a second investigator confirming interpretation and coding by independently reviewing sections of data [31, 32]. Refinement of the coding scheme was discussed between the investigators until consensus was reached.

Results

Interview participants ($n=26$) included nephrologists from transplanting centres (15%), nephrologists from regional, rural, or remote non-transplanting centres (19%), clinical pharmacists (19%), and nursing staff (19%). Most participants (73%) had >7 years of experience in their profession, and just over half (54%) were based in regional, rural, or remote areas. Most participants (65%) reported using telehealth as a modality for provision of transplant care in their roles. Demographic characteristics of participants are included in Table 1.

With regards to the barriers and difficulties faced by regional, rural, and remote patients in accessing kidney transplantation, identified themes, subthemes and illustrative quotations are presented in Table 2. Participants also provided recommendations for new or modified service delivery models, summarised in Table 3. Themes identified centered around communication, geographical distance from treatment, healthcare inequities, social and financial disadvantage, and lack of local services.

Ineffective communication and education

Overcoming limitations of telehealth

Participants had concerns around the utility of telehealth, as “with some people you can’t do Teams, so there’s a cohort of patients who don’t have the IT literacy”. Others also pointed out the limitations of telehealth, stating “it’s actually very difficult to do a thorough review and assessment of a patient via telehealth”. Participants reported “this patient cohort is very challenging to build rapport and to communicate with over a computer in a telehealth scenario”.

Language and cultural barriers

Language barriers were commonly cited as contributing to poor communication between clinicians and patients, as “for some of them English is not their first or even second language, so that can be difficult”. Participants also highlighted barriers due to cultural differences, as “they might feel shame” or fear around asking questions about transplantation. Participants felt “they’re not used to

Table 1 Demographic characteristics of participants

Health professional characteristics	Value ($n=26$)
Profession	
Nephrologist (based in kidney transplantation unit)	4 (15%)
Nephrologist (based in regional, rural, or remote non-transplanting centre)	5 (19%)
Clinical pharmacist	5 (19%)
Nursing staff	5 (19%)
Social worker	2 (8%)
Indigenous liaison officer	2 (8%)
Psychologist	1 (4%)
Transplant surgeon	1 (4%)
Senior medical officer	1 (4%)
Years of experience	
0–7 years	7 (27%)
8–14 years	12 (46%)
>14 years	7 (27%)
Rurality of principle place of practice (MMM 2019)	
Metropolitan Area	12 (46%)
Regional Centre	9 (35%)
Large Rural Town	1 (4%)
Remote Community	1 (4%)
Very Remote Community	3 (11%)
Use of telehealth for provision of care	
Yes	17 (65%)
No	9 (35%)

Table 2 Themes and subthemes identified and illustrative participant quotations

Themes	Quotes
Ineffective communication and education	
Overcoming limitations of telehealth	<p>"With some people you can't do Teams, so there's a cohort of patients who don't have the IT literacy, I suppose to do Teams education." (Nur; Metro)</p> <p>"I think where there is any health literacy or language barriers, they tend to compound over telehealth.. I think that's very often reflected in, patients will go and they will sit, but later on their memory of what happened just isn't as good." (Med; Rem)</p> <p>"I think that it's actually very difficult to do a thorough review and assessment of a patient via telehealth and particularly this patient cohort is very challenging to build rapport and to communicate with over a computer in a telehealth scenario. It's almost impossible to build rapport, and then it's very challenging for that two-way communication to occur effectively." (Phar; Reg)</p>
Language and cultural barriers	<p>"Obviously some of it is the language because for some of them English is not their first or even second language, so that can be difficult." (Sur; Metro)</p> <p>"They're not fully engaged with the health service and so they don't know how to utilise the health service appropriately and their understanding of their illness, isn't there. They're not used to trying to manage their healthcare in such a structured way that's required for transplant patients." (Nur; Rem)</p> <p>"I think their ability to ask questions is limited. And there's a lot of questions that come and a lot of questions they might feel shame about asking in that setting, whereas they don't in that smaller setting, and shame is a big put-er-off-er of communicating." (Nur; Reg)</p>
Limited awareness of treatment options	<p>"They have no expectation that they could be considered for transplant, that's really the biggest barrier. They are so demoralized when they come on to dialysis, when they realise that they've got renal failure.. So to make that change, "oh actually perhaps I could have a kidney transplant" is beyond their concept." (Soc; Reg)</p> <p>"I think a discussion about the risks of what can happen post-transplant is important, so that patients are aware of what the trajectory may be afterwards. I think that can be difficult because patients might not understand that after having a transplant, they're not necessarily free to go back home and stay home, that it does involve still frequent visits to a hospital. And sometimes that course can be quite rocky afterwards." (Phar; Reg)</p> <p>"I think the patients are really facing transplant like it's the golden egg and then if things don't go well or they have an unexpected reaction to having someone else's kidney in their body, or guilt over someone else's kidney.. their mental health can really be prone to deterioration." (Psych; Reg)</p> <p>"We already know that when patients are on dialysis, their cognition is not at the best. It's really unideal that these conversations are happening at dialysis, but unfortunately that's just the set up at the moment." (Neph; Rem)</p>
Frustration with education provided	<p>"We know with people, in particular people with poor health literacy, it needs to be more than once, all the information needs to be repeated and repeated and repeated. I really think that a significant number of my patients cannot retain everything that they're told in a one-off seminar. They just don't have the background medical knowledge to do it." (Neph; Rur)</p> <p>"I've had them dial into those transplant webinars that they do for the patients, too high level. I had to basically sit through and explain everything when we dialed into one of them. It's too hard for them to understand. (Nur; Rem)</p> <p>"I think it's also difficult to understand the level of comprehension. So whilst you might have a lot of conversations talking about pre transplantation medications or requirements or the process, it doesn't necessarily mean that that was comprehended, because you may then need to have the exact same conversation later, or there was some missing in translation." (Phar; Reg)</p>
Overwhelming geographical burden	
Struggling to access to work-up and assessment	<p>"There is a push for the ANZDATA quality indicator report, one of their KPI's is patients being worked up within six months of starting dialysis for transplant. That is just unachievable in the area that I work. That would never happen, and that is just simply because these patients live thousands of kilometres away from where they can get their cardiac investigations, or the bone mineral density scan, and they all have dental problems. So we're always going to be underperforming there." (Neph; Rem)</p> <p>"If people are 8 h away from [metropolitan city] to ask them to come down for a transplant assessment clinic, that's not so reasonable. Because if they're a dialysis patient, you have to not only coordinate dialysis, you have to coordinate accommodation, you need to accommodate patient travel, you have to come with a carer, and you need to organise your medications." (Phar; Metro)</p> <p>"We do have CT and ultrasound and echo and stress echo here, but some of the wait lists are quite long. We don't have private services to put people through, it's all just government wait list, dentist as well." (Med; Rem)</p>
Coping with trying circumstances	<p>"When patients come down from [state] to us, they're petrified, absolutely petrified because they've never been to [metropolitan city] before, they've never been to the hospital before. They might not have even flown on a plane before.. And that's a big thing." (Nur; Metro)</p> <p>"Ischaemic time is a problem. For our guys from the [remote area] to get down there, you're looking at no less than 12 h to get down there.. So that means cold ischaemic time, delayed graft function, increased risk of rejection and they're already at a higher risk of rejection as it is." (Nur; Reg)</p> <p>"Sometimes there's quite a big delay in getting them actually down for their transplant. Which obviously increases that ischaemic time which increases delayed graft function." (Sur; Metro)</p>

Table 2 (continued)

Themes	Quotes
Dislocation from home, country and family	<p>"I think definitely it's a huge deal for patients being off country and away from supports, specifically at a time when there's a large and stressful event that's happening." (Med; Rem)</p> <p>"We have a lot of patients who are displaced, so they're not in their home community. Which has got to be heartbreaking for them. It's got to affect their health not being where they want to be with their family. We've got a number who are very lonely, they're here maybe with an escort. Sometimes their escort goes home and they're by themselves. I think that's a big barrier and that also feeds into them looking after themselves as well. And their priority is not what's going on with their health, their priority is wanting to go home." (Phar; Reg)</p> <p>"There's nothing for them here basically, there's nothing, they're ripped away from family and country. They get angry, they get sad. Some people turn to drinking. Even if they don't want to, they're trying hard not to drink, but because there's a cohort of people from community they're drawn to them.. And because they're lonely and then they end up going along with having a few drinks and missing dialysis, missing medical appointments." (Soc; Reg)</p>
Fighting for equal opportunities	
Perpetuation of institutional racism	<p>"There are challenges. There are technical comorbidity associated challenges to do with hepatitis, diabetes, heart disease, vascular disease, absolutely right. I'm not shying away from that, and yet people get transplanted with those comorbidities in inner city [metropolitan city], but not if you're black in [remote area]." (Neph; Metro)</p> <p>"We collocate indigenous status and non-compliance. It turns out non-compliance is unfortunately, a relatively common part of any chronic illness, including the post-transplant journey. There's a lot of non-compliance, some of it amongst indigenous Australians, that's true. Also, the same sort of proportions amongst non-indigenous Australians. But the problem is that we collocate those two things with indigenous status and that is still widely prevalent today. How can I give you a kidney if you won't take your tablets, or you won't attend dialysis? But underlying that is this under communication and miscommunication. It is effectively a form of both individual and systemic racism, in my view." (Neph; Metro)</p> <p>"There's a lot of reasons why people are not compliant, we've had a lady that recently has had a transplant and now it's doing well. But in the previous five years, she wasn't taking any of her medications because she's got young children, was a partner that suffered domestic violence and abuse. You've got no time to go to the pharmacy and pick up your tablets when you're dealing with all of these social issues." (Phar; Metro)</p> <p>"I've had experience previously where I've had an Aboriginal gentleman and his sister who was also Aboriginal wanted to donate, and they really blocked it, blocked it, blocked it, blocked it because they didn't want an Aboriginal person as a donor." (Nur; Rem)</p>
Gatekeeping transplant opportunities	<p>"There's no equity amongst the country, so how can you smoke in [state] but you can't smoke in [state] when the goal is the same? Likewise, if you've got a bit more weight on you, elsewhere you'd get a transplant, but [state] you can't because they're strict on body mass.. They wanted to see everyone that was 36 to 38 on the BMI or under, and then they still turn them all away anyway. So why say you'll be happy to see them if you're going to turn them away?" (Nur; Reg)</p> <p>"With living related, I find they really, really block it and it make it twice as hard. And then they kept coming up with reasons why, they kept saying to her she's too fat and really she was a size 12, not a lot of central adiposity. It was just, it was devastating. And that was two years of hard work to try and get them there." (Nur; Rem)</p> <p>"Each step in the journey just takes longer, and sometimes that time is what results in things happening to them that effects their suitability. So the longer they sit on dialysis, they just sort of end up getting more problems." (Med; Rem)</p> <p>"Then you have the other patients who maybe they'll say to you, "how come nobody's ever talked to me about transplant?" And that's very upsetting." (Soc; Reg)</p>
Incomprehension of inherent disadvantage	<p>"I think the locals know exactly what the difficulties are, and it's these ivory tower, metropolitan transplants professionals "well I'll tell you how I do it in my unit". We're the ones with the problem." (Neph; Metro)</p> <p>"I think some of the attitudes towards our indigenous patients are a bit ordinary at [metropolitan hospital]. I think there is an expectation that a remote area patient has the same resources as a person who lives in [metropolitan area], that a person from a remote area has the same health literacy as someone who comes from [metropolitan area]. Then they're all benchmarked on a [metropolitan area] patient and our patients are not from [metropolitan area], they are from remote area communities and they have completely different needs and they need a lot more time and energy put into them than meeting them at transplant assessment clinic for 30 min. And then they wonder why the patients don't engage, and it's because you don't have that relationship with them." (Nur; Reg)</p> <p>"It still seems like there's a lack of understanding about where these guys are coming from and what they've been through and how hard it is to get them to that point. And then they go down there and they get told, "oh you need to lose two more kilos", or "you need to do another heart test" or this or that or "your sugars are too high, go back and work harder". (Nur; Rem)</p>
Paucity of social support	

Table 2 (continued)

Themes	Quotes
Seeking safe and reliable support	<p>"Not everyone has an escort, and so what do those people do? How do they get through the system at [metropolitan hospital] if they don't have a support person and it's frowned upon, it's looked down upon, but some people just don't have someone who can have six weeks off work, so that has been quite hard." (Nur; Reg)</p> <p>"Some people don't even have availability to an escort. The escort is just not there. A person has their own life to live, so they need someone trusted and responsible with them. There's a lack of those support people." (Soc; Reg)</p> <p>"It's trying to find someone that you think will be able to leave the community for two months or three months, and often someone will identify themselves and then they might pull out. So you often work through and have to find two or three people that would be willing to leave because everyone that's actually quite functional, and this is probably not just rural or remote, everyone that's functional that can manage that responsibility of caring for someone else often already has a responsibility for caring." (Nur; Rem)</p>
Pervasive psychological distress	<p>"It's been suggested that we refer some of our patients for a psychiatric review, when really I think what they mean is that this person is anxious and could do with seeing a psychologist. But again, if it's going to be a psychologist, I think it would be helpful for that psychologist to have an understanding of their journey that they're facing and the significance of that potential life impact." (Med; Rem)</p> <p>"Well their loneliness and they need people around them. If you look at someone going through such a big procedure and to keep their emotional health safe so that they can physically deal with the issues, you have to have your mind in the right place as well." (Soc; Reg)</p> <p>"The thing is we're talking about something that's life changing, but also are they going to actually come through the operation? Are they going to survive? And then once they have survived, the support, because every day going to the hospital, every day worrying about what is ahead of them." (Soc; Reg)</p>
Reluctance to abandon responsibilities	<p>"A lot of them just, they have to refuse. They've got kids to look after at home and if their husbands are away for months on end, they've got no one else to watch their kids." (Phar; Rem)</p> <p>"They're still maybe having people come to check on the home or doing things, because of the sort of sense of relocation. So the social support not just where they're from, maintaining things like the childcare or the house or the bills or anything at home, or if they've got caring responsibilities, not just children, but maybe elderly parents." (Soc; Metro)</p> <p>"It just depends on the families. If you've got your own family back at home, who's going to care for that family? So that could be if you have children, not everyone has anyone who can support the family." (Soc; Reg)</p>
Crushing financial peril	
Contending with unexpected expenses	<p>"So often even to get them to go down for work up stuff, they'll only do that on pay week, because otherwise they don't have enough money. You might get your accommodation and airfare or transport paid for, but then they have to pay for food and they're used to living off bush tucker or rice or something really cheap in the community that they share with family. Whereas in [regional centre] they actually have to go and buy stuff which they can't afford." (Nur; Rem)</p> <p>"Some of the challenges with transplant work up are access to investigations. I know all this stuff is supposed to be Medicare bulk billed, but most of the places that are providing these tests are private radiology companies." (Neph; Rur)</p> <p>"They have to fork out money to buy all the transplant medications and some of them are actually not financially prepared for that. So financial barrier, from probably buying medications post-transplant that's pretty expensive." (Neph; Reg)</p>
Scarcity of financial assistance	<p>"Most of them are still paying for rent at home and then having to pay for the additional accommodation cost. Most accommodations here are between \$140 up to about \$220. Only \$70 is covered for that accommodation. So that's a massive gap." (Soc; Metro)</p> <p>"Money is the big one at the moment, so we know that it's going to cost them money to go for a transplant. They need money to get to and from [regional centre] airport. They need money to get to and from [metropolitan city] airport. They need money for food, they need to cover their rent while they're here, and while they're down there, they got to pay their rent up here. They've got to pay any out-of-pocket expenses for accommodation down south. Food tends to be a bit more expensive because they don't have their normal pantry supplies that they have up here. So I think the guideline has sort of always been around \$1500 to \$2000 that you need in your pocket for that." (Nur; Reg)</p>
Juggling competing priorities	<p>"If you haven't got enough money to pay for your food and haven't got enough money to pay for your rent, people will come and they say 'I need that money for something more important to me than it is to you'. And then all of a sudden you're not feeding or you're not housing, then your pills are a long way down the list of priorities. You've got to keep the family safe and fed." (Neph; Metro)</p> <p>"When you tell them they'll be coming every day, if they can't take time off work you've got to talk to them about that stuff. That, I think is the biggest thing, because it's also the biggest thing that impacts their finances if they're not working post-transplant, or for some of them if they've got their own business or casual work." (Nur; Metro)</p> <p>"We're talking about people who live day-to-day. Who again, talk about health literacy, what about financial literacy? 'How can I save? I don't know how to save', and again if you think about the collective society of Indigenous people, people don't squirrel away their own money. They share their money, so saving is not something that's comprehensible to them. And then for the non-Indigenous people, maybe people who are working, who are living day-to-day, paying rent for where they live, paying a mortgage for where they live, and now they've also got this added expense." (Soc; Reg)</p>
Deprived of adequate local care	

Table 2 (continued)

Themes	Quotes
Absence of skilled and stable services	<p>"One challenge we do have is the complete lack of mental health services, and drug and alcohol type services. I've got a few people with major trauma backgrounds, and there's just nothing for them. There's no way that they can get past the trauma to be organised enough, and then well enough with regards to adherence and diet and maybe losing some weight." (Neph; Rur)</p> <p>"We don't really have any support for heavy dietetic input or there's not really any ability for us to refer to exercise physiologists or for them to even see anyone privately.. They don't even exist in the area I work, some of the places like [remote area] doesn't even have a gym, so they can't use effective exercise to lose weight." (Neph; Rem)</p> <p>"At the moment in [regional centre] they don't have a routine appointment with the psychologist following the transplant. And I think it's probably to do with workload and capacity, but I think that's a real area that needs to be refined.. There's certainly a steady stream of post-transplant patients coming through ED following self-harm or suicidal ideation.. But that post care isn't being well serviced." (Psyc; Reg)</p> <p>"I wish I had more time to sit with them and talk about transplant, but when I do go to see the dialysis patients, I usually do that on a very quick outreach trip.. So it's quite challenging to see eight patients within two to three hours.. And to have a decent chat with them and explain transplant can be quite challenging." (Neph; Rem)</p> <p>"So partly it's you've got fewer services, but also you've got very high turnover services, it's very few local people have all the expertise, and then the people who do come don't stay." (Neph; Metro)</p> <p>"They have a lot of trouble with staffing there as well as retaining staff. So we're always liaising with different people who don't understand what they need to be doing and the importance of getting this and that done." (Nur; Metro)</p>
Concern around treatment delays	<p>"They don't have pathology on site, they just have i-STAT machines. A challenge is sometimes with the pathology and how long it takes to get to [regional centre], especially in these areas that don't have pathology because the sample can degrade. Often the tacrolimus levels and the more fancy tests take up to a week to come back." (Neph; Rem)</p> <p>"It's difficult from a medical point of view because we may have concerns on a blood test that's taken 40 to 48 h to receive and concerns about complications are high." (Neph; Reg)</p>
Chaotic medication governance	<p>"I was always insistent that they had at least two weeks of medications up their sleeve, because those remote communities like [remote area] and [remote area], they do get flights in there, but you get a cyclone going through and you mightn't have a flight that week." (Phar; Reg)</p> <p>"Storage is a huge issue. It's hot as hell up there and not everyone has a fridge in their house or electricity. So you're not keeping these meds below 25 degrees. They're getting up to 40 degrees." (Phar; Rem)</p> <p>"We got caught out one time where a patient was in [remote area] and we weren't sure if they had neutropenia. There were no flights out for the whole entire weekend because Qantas changed their schedule for flights, so we couldn't check their pathology and there also was no GCSF in [remote area] or that particular area. So if it was real and he developed fevers, or just we just felt like we should treat, we just didn't have that option. And there were no flights, so how would we get that medication in?" (Neph; Rem)</p> <p>"There's a lack of healthcare professionals in certain regional areas that have an understanding of the importance of medications post-transplant. Therefore, patients need to be able to advocate for themselves, for their health, but sometimes that can be difficult for patients who have a distrust of the healthcare system or they don't feel confident in their ability or they have a lower health literacy to be able to do that." (Phar; Reg)</p> <p>"They have different primary healthcare providers in these communities.. If the patient goes and sees an [FIFO health service] doctor and they want to prescribe them or change their Webster pack and they don't have an understanding of tacrolimus, a mistake can happen there, or they use a different EMR so they will have a different medication list to what we're using on the [state public health system] EMR, and then the patient once again gets confused, which I don't blame them because I'm confused as well. There's just all these areas where mistakes can happen." (Neph; Rem)</p> <p>"Liaising with community pharmacists gets quite complicated. Writing the script incorrectly is very simple to do. Even just doses change, and then the paper trail of the dose changing can be different and it can be difficult to keep up with it and medication errors happen across the board all over the place." (Neph; Reg)</p> <p>"Making sure they're not changing brands of medications because that's become such a challenge when they go back to community pharmacies and taking one brand for one strength and one brand for another." (Nur; Metro)</p>

Abbreviations

Neph – Nephrologist, Nur – Nursing Staff, Med – Medical Officer, Sur – Transplant Surgeon, Phar – Pharmacist, Soc – Social Worker or ILO, Psyc – Psychologist, Metro – Metropolitan Area, Reg – Regional Area, Rur – Rural Area, Rem – Remote Area

trying to manage their healthcare in such a structured way" when it comes to the many tests and appointments required as part of the transplant journey.

Limited awareness of treatment options

Participants highlighted that often patients "have no expectation that they could be considered for transplant", demonstrating a lack of awareness around transplantation as a potential treatment option. They felt there is

sometimes misinterpretation or unrealistic expectations around transplantation processes and outcomes, particularly as "patients might not understand that after having a transplant, they're not necessarily free to go back home and stay home, that it does still involve still frequent visits to a hospital". Participants also highlighted that "when patients are on dialysis, their cognition is not at the best" and there were concerns around how this may limit their

Table 3 Participant recommendations for new or modified service delivery models and existing examples

Recommendation	Suggestions & Considerations	Evidence
Earlier identification, education and referral	<ul style="list-style-type: none"> Earlier discussion with patient around interest in and suitability for transplant as a treatment option to enable timely referral. Starting transplant education earlier in CKD journey, addressing problematic behaviours or lifestyle choices prior to dialysis commencement. 	KDIGO (38)
Changing the way education is delivered	<ul style="list-style-type: none"> Repetitive or staged education to increase engagement and retention. More information around potential risks or poor outcome. Targeted to rural and remote patients to ensure they are prepared for additional costs, travel etc. Outreach trips to provide education and build rapport with communities. Culturally appropriate delivery of education for ATSI consumers, yarning circles, visual resources, health worker delivery. 	Low et al. (42); Jesse et al. (43); NIKTT (39, 40); QKTS (41)
Coordination of work-up testing	<ul style="list-style-type: none"> Booking screening tests and appointments together to allow completion in one trip away from home. 	Formica et al. (44) Kidney Health NZ (45)
Outreach visits for transplant assessment	<ul style="list-style-type: none"> Ensure patient still visits transplant hospital at least once for familiarization purposes. Enable patients and family to engage and communicate more comfortably and without recurrent travel. Enable transplant team to experience home/community environment and services available while building rapport with patients. Engagement and upskilling of local health service staff to improve local provision of transplant care and strengthen relationships with primary care providers. 	NIKTT (39, 40)
Increased psychosocial support	<ul style="list-style-type: none"> Increased involvement of social worker and psychologist in transplant work-up. Health professional navigator to help support and advocate for patients through the transplant process. Increased psychologist support post-transplant. 	NIKTT (40); Purple House – Social support 'Malpas' (49)
Culturally appropriate support staff	<ul style="list-style-type: none"> Both male and female ILOs, health workers and clinicians. Increased access to interpreters for NESB patients. More involvement of ILOs, health workers during transplant work-up process and assessment. 	NIKTT (40)
Peer mentoring and support (pre and post)	<ul style="list-style-type: none"> Providing lived experience perspective that cannot be delivered by health care professionals. Mentors need to be carefully selected to minimise risk of misinformation. Ensure mentors are also well supported to minimise any risk to their wellbeing. Consideration of using mentors with both positive and negative transplant outcomes to minimise bias. 	Sullivan et al. (51) NIKTT – Compass (39, 40); Purple House (50)
Increased local services and resources (pre and post)	<ul style="list-style-type: none"> Increased local support staff with appropriate level of transplant knowledge to assist with education, coordination of work-up testing etc. Increased use of telehealth for follow-up transplant assessment and post-transplant reviews rather than repeated travel. Access to MDT during transplant work-up – pharmacist, social worker, ILO, psychologist, dietitian, physiotherapist. Earlier return to home nephrology service, better engagement with primary care providers to enable collaborative shared care model locally. Access to pathology on-site or POC testing to prevent delay in obtaining results. Ensuring streamlined and uninterrupted access to medications. 	CYKC Team (56); NIKTT (40); Al Ammary et al. (54); Huuskes et al. (53); Lambooy et al. (52)
Increased financial support	<ul style="list-style-type: none"> Nil out of pocket expense for accommodation, or purpose-built accommodation on hospital grounds. Transport provided with nil out of pocket expense. Reduced costs associated with medication supply. 	QLD Gov (46); Mathur et al. (47); Kangga-wodli (48)
Individualised transplant protocols	<ul style="list-style-type: none"> Broader infection screening, targeted antimicrobial prophylactic regimens post-transplant. Pharmacogenomic testing to target immunosuppression regimens to specific patients. 	Ho et al. (57); Cheung et al. (59); Alvaro et al. (58)

Table 3 (continued)

Recommendation	Suggestions & Considerations	Evidence
Building a sustainable work force for a new regional transplant service	<ul style="list-style-type: none"> Consideration of other support services required outside of transplant unit – ICU, interventional radiology, histopathology etc. Recruitment of experienced transplant healthcare professionals to manage high risk patient cohort, build community confidence. Adequate rotational surgical roster to prevent burn out. Consideration of logistics around organ retrieval processes to ensure timely implantation at regional centre. Collaboration with metropolitan transplant unit for clinical support and advice where required, allow management of complications locally. 	N/A

ability to engage with discussions around transplant and education provided.

Frustration with education provided

The delivery of transplant education was frequently cited as being problematic for this patient cohort, with one participant explaining “I’ve had them dial into those transplant webinars that they do for the patients, too high level. I had to basically sit through and explain everything”. There was also frustration around the format of delivery, as “it needs to be more than once, all the information needs to be repeated and repeated and repeated”, because “patients cannot retain everything that they’re told in a one-off seminar, they just don’t have the background medical knowledge to do it”.

Overwhelming geographical burden

Struggling to access to work-up and assessment
 Participants highlighted the difficulties faced by these patients in terms of being able to access the required tests for transplant work-up and assessment, including the need for recurrent travel given “these patients live thousands of kilometers away from where they can get their cardiac investigations, or the bone mineral density scan”. One participant emphasised that “if people are 8 hours away from [metropolitan city] to ask them to come down for a transplant assessment clinic, that’s not so reasonable”. The long wait times associated with publicly funded healthcare services for things like cardiac screening and dental was also mentioned, as “some of the wait lists are quite long”.

Coping with trying circumstances

The issue of patients and carers having to navigate unfamiliar cities and health services when travelling to transplant facilities was frequently mentioned, with one participant stating “when patients come down from [state] to us, they’re petrified, absolutely petrified because they’ve never been to [metropolitan city] before, they’ve never been to the hospital before. They might not have even flown on a plane before.” The difficulties transporting patients to transplant facilities in a timely manner was also cited as an issue, with one participant explaining “ischaemic time is a problem. For our guys from [remote

area] to get down there, you’re looking at no less than 12 hours to get down there.”

Dislocation from home, country and family

In addition to the logistic issues around distance, participants also emphasised the emotional and psychosocial toll on patients “being off country and away from supports, specifically at a time when there’s a large and stressful event that’s happening”. One participant also highlighted how isolation from loved ones and community can lead to risky behaviours that may ultimately affect patients’ health and wellbeing, stating “they’re ripped away from family and country. They get angry, they get sad. Some people turn to drinking”.

Fighting for equal opportunities

Perpetuation of institutional racism

Participants noted the ongoing lack of investment when it comes to ensuring equitable access to kidney transplantation for Indigenous Australians. One participant acknowledged “there are technical comorbidity associated challenges” but pointed out “yet people get transplanted with those comorbidities in inner city [metropolitan city], but not if you’re black in [remote area].” It was also noted that “we collocate Indigenous status and non-compliance” even though “underlying that is this under communication and miscommunication.” One participant highlighted the perceived difficulties around living donor kidney transplant (LDKT) for Indigenous Australians, sharing an experience where they believed it was “blocked” by the transplanting centre because “they didn’t want an Aboriginal person as a donor”.

Gatekeeping transplant opportunities

The tendency for transplanting centres to gatekeep when deciding patients’ eligibility for transplant was highlighted by participants, who noted the inconsistencies in eligibility criteria. For example, “how can you smoke in [state] but you can’t smoke in [state] when the goal is the same?”. Participants emphasised “the longer they sit on dialysis, they just sort of end up getting more problems”, highlighting the drawn-out assessment process for rural and remote patients can ultimately affect their eligibility for transplant. The fact that transplant does not

seem to be discussed with all patients was also raised by participants, who have been asked by patients "how come nobody's ever talked to me about transplant?"

Incomprehension of inherent disadvantage

When it comes to the metropolitan transplant centres' eligibility assessment for this patient cohort, "it still seems like there's a lack of understanding about where these guys are coming from and what they've been through and how hard it is to get them to that point". It was also felt that there is a lack of acknowledgement from transplanting centres regarding the "completely different needs" of rural and remote patients, as "they need a lot more time and energy put into them than meeting them at transplant assessment clinic for 30 minutes".

Paucity of social support

Seeking safe and reliable support

The difficulty associated with patients finding a suitable support person was highlighted, with one participant explaining "it's trying to find someone that you think will be able to leave the community for two months or three months" as often the people who are identified as being a suitable escort will have work or family responsibilities of their own that they cannot leave.

Pervasive psychological distress

Participants felt that the psychological stress associated with going through a kidney transplant is a significant issue for these patients, highlighting "we're talking about something that's life changing", but it is not without risk, so "are they going to come through the operation? are they going to survive?". Another participant stated how important it is "to keep their emotional health safe" so they're in the right mindset to look after their physical health also.

Reluctance to abandon responsibilities

For some patients, being able to find someone to manage the day-to-day responsibilities at home, while they are away can also present a barrier to transplant. As one participant pointed out "if you've got your own family back at home, who's going to care for that family?". For some patients "maintaining things like the childcare or the house or the bills or anything at home" or "caring responsibilities" may take priority over their own health.

Crushing financial peril

Contending with unexpected expenses

Participants highlighted some of the unexpected expenses associated with transplant that patients and their families are faced with, explaining "you might get your accommodation and airfare, or transport paid for, but then they have to pay for food, and they're used to

living off bush tucker or rice or something really cheap in the community that they share with family". Another participant stated, "they have to fork out money to buy all the transplant medications and some of them are actually not financially prepared for that".

Scarcity of financial assistance

The inadequacy of current subsidies offered through the public health system for travel and accommodation costs was frequently cited by participants as being out of touch with current costs of living. According to one participant "most accommodations here are between \$140 up to about \$220 (per night)", yet "only \$70 (per night) is covered for that accommodation". One participant emphasised the additive effect of these out-of-pocket expenses over time, explaining "around \$1,500 to \$2,000 that you need in your pocket for that".

Juggling competing priorities

Another issue contributing to the overall financial burden of transplant is the fact that many patients are managing other competing financial priorities, for example, "people who are working, who are living day-to-day, paying rent for where they live, paying a mortgage for where they live, and now they've also got this added expense". Obligations to employers or businesses can also present an issue for some "if they can't take time off work", as that makes attending scheduled appointments difficult.

Deprived of adequate local care

Absence of skilled and stable services

Participants cited issues with available staffing and services as being significant barriers to providing local transplant care. Lack of support services like psychology, dietetics and physiotherapy were mentioned, with one participant explaining "I've got a few people with major trauma backgrounds, and there's just nothing for them". With regards to staffing one participant explained "very few local people have all the expertise, and then the people who do come, don't stay". Particularly in the more remote locations, participants said "we're always liaising with different people who don't understand what they need to be doing and the importance of getting this and that done". Time constraints faced by clinicians was also mentioned by participants, "I wish I had more time to sit with them and talk about transplant".

Concern around treatment delays

In many remote communities "they don't have pathology on site, they just have i-STAT machines" which means only a limited range of tests can be completed. The potential consequences of having a significant delay in obtaining formal pathology results was highlighted by participants as a significant concern. One participant

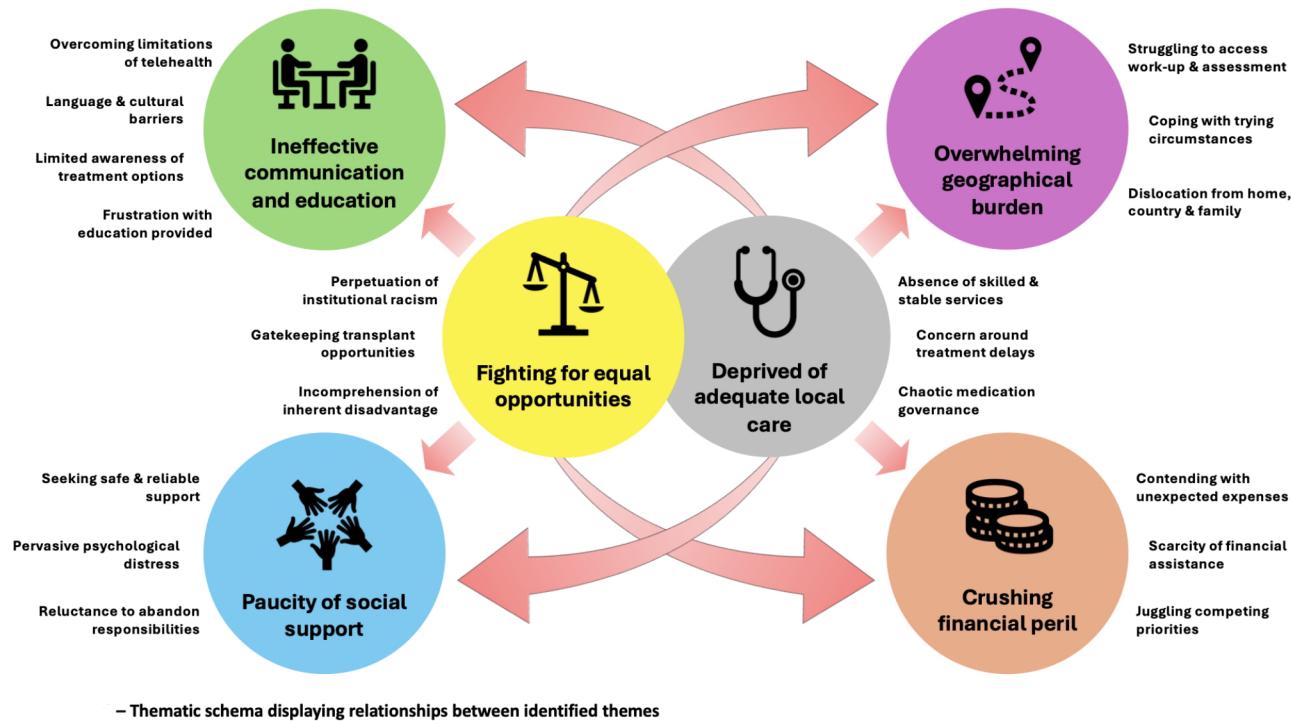


Fig. 1 Thematic schema displaying relationships between identified themes

explained “it’s difficult from a medical point of view because we may have concerns on a blood test that’s taken 40–48 hours to receive and concerns about complications are high”.

Chaotic medication governance

There were significant concerns raised by participants around the complexity of ensuring ongoing medication supply in some rural and remote communities. Issues with transportation of medications was highlighted, as “they do get flights in there, but I mean you get a cyclone going through and you mightn’t have a flight that week”. Appropriate storage of medications can also be problematic, as one participant explained “it’s hot as hell up there and not everyone has a fridge in their house or electricity”. Some participants were also concerned about the “lack of healthcare professionals in certain regional areas that have an understanding of the importance of medications post-transplant” as well as the burden associated with “making sure they’re not changing brands of medications, because that’s become such a challenge when they go back to community pharmacies”. The additional risk associated with having multiple care providers and prescribers was described, with one participant explaining how this has caused medication discrepancies and errors as they all “use a different electronic medical record so they will have a different medication list”. Concerns were also raised around inexperienced clinicians adjusting medication regimens for transplant patients,

because if they “don’t have an understanding of tacrolimus, a mistake can happen there”, emphasising that “there’s just all these areas where mistakes can happen”.

Discussion

The objective of this study was to explore kidney transplant health professional perspectives to understand current barriers to kidney transplantation for patients in regional, rural, and remote areas of Australia, and to identify ways in which access, experiences and outcomes could be improved. Health professionals in this study explored numerous patient specific and system level barriers to kidney transplantation stemming primarily from the overarching lack of locally available services and financial and social disadvantage experienced by these patients. The connection between the identified themes in this study are displayed in Fig. 1.

Unsurprisingly, health professionals who were based in, or had experience providing care within rural and remote communities had a more comprehensive understanding of barriers to transplantation at the local level and the adversities faced by this patient population. Many of the barriers explored in this study resemble those discussed by health professionals worldwide in previous studies. In a study looking at access to all forms of KRT for rural populations, issues around extensive travel, financial stressors, lack of social support, and inadequate local resources were mentioned by clinicians [26]. Similarly, in North America it has been found that inadequate social

support, geographical distance, communication and education difficulties, as well as limited local healthcare resources are also major barriers to kidney transplantation for rural and remote populations [21, 23, 24]. In Europe, many of the same patient level and system level barriers have been identified with regards to accessing all forms of organ transplantation [33, 34]. Once again, issues around lack of social support, financial strain, distrust of health systems and inadequate education (patient level) and lack of resources and support staff (system level) are highlighted [33, 34], supporting the findings of this study. However, the concept of inequities in waitlisting and bias against certain patient groups explored in this study, has previously only been discussed in the context of ethnicity (such as Indigenous or migrant populations) [22, 35, 36], or LDKT specifically [37].

This study also provides a range of recommendations from participants for addressing barriers to access and improving experiences of kidney transplantation for regional, rural, and remote populations (Table 3). The recommendation around earlier discussion and referral for transplant as well as earlier commencement of transplant education is in line with Kidney Disease Improving Global Outcomes (KDIGO) guidelines for management of transplant candidates, which recommends commencing transplant discussions once eGFR < 30mL/min/1.73m² [38]. However, timely referral for kidney transplantation can be hindered by the inherent disadvantage faced by rural nephrologists, as they are removed from transplant units, have smaller groups of physician colleagues and limited access to professional development and education opportunities [23]. With regards to changing the way transplant education is delivered, the National Indigenous Kidney Transplantation Taskforce (NIKTT) and the Queensland Kidney Transplant Service (QKTS) have trialed the use of more culturally appropriate education formats for Indigenous Australian patients, including the use of yarning circles and tailored written resources with promising findings [39–41]. Improved communication and education for potential transplant candidates has also been highlighted as a priority for action across European countries as a strategy to improve access to transplantation [33]. Several other studies have tested novel transplant education delivery programs or formats, also with positive results with regards to patient acceptability and some improved post-transplant outcomes [42, 43].

Coordination of transplant work-up testing was a recommendation made by participants and this has also been trialed previously in the United States, with significantly reduced time to transplant waitlisting for patients [44]. A kidney transplant centre in New Zealand has also recently implemented a one-day work-up program, significantly increasing the number of patients waitlisted

for transplantation [45]. Outreach visits by the transplant team for assessment and education was recommended in this study, with some reporting that this is already part of the standard provision of transplant care within their health services. Outreach visits for kidney transplant assessment was another intervention trialed by NIKTT, which led to an increase in patients commencing work-up and becoming active on the waitlist, as well as increasing the number of patients transplanted [39, 40]. Increased financial support for patients and their families was recommended by study participants, with existing studies and support/subsidy schemes including living kidney donors only [46, 47]. However, there are existing services within Australia that provide transport and/or accommodation for patients with no out-of-pocket expenses, while they are away from home accessing health services, although it is important to note that some of these services are available for specific patient groups only [48, 49].

Increased psychosocial support was a recommendation of this study, including the addition of a health professional 'navigator' role and more culturally appropriate support staff for Indigenous Australian patients. Several of these programs were trialed by NIKTT in different locations, however staffing issues and COVID-19 restrictions significantly impacted these projects [40]. Again, this is a service that is already offered by some Indigenous-run kidney health services [49]. The recommendation for increased use of 'peer mentors' or 'patient mentors' as a valuable source of support for patients both pre- and post-transplant was frequently mentioned, and is a resource routinely used within some kidney health services [50]. Studies investigating the use of 'patient mentors' in the kidney transplant space have yielded positive results for both the mentors and mentees, with positive experiences for both and improved access to transplant work-up and waitlisting [39, 40, 51].

It was clear in this study that increased local services and resources are needed. While telehealth is a modality that garners mixed reviews, based on recommendations from this study and existing research it appears that there is still a role for its' use in improving access to kidney transplant care if used in appropriate settings [52–55]. However, this does not replace the need for face-to-face local services, especially given nephrologists practicing in rural settings are more likely to consider the complexities of post-transplant management in the absence of local transplant services when deciding whether to refer patients for KT [23]. The delivery of community-focused multidisciplinary specialist kidney care within remote communities has also been shown to increase consumers engaging a service that was previously only offered via telehealth [56].

The recommendation of individualising immunosuppressant regimens for rural and remote kidney transplant populations is still a developing concept. Thus far, pharmacogenomic screening along with other novel diagnostic tools have been used to successfully develop personalised immunosuppressant regimens [57–59], although further trials are required to clarify beneficial clinical outcomes. Furthermore, a trial is underway investigating the feasibility and acceptability of a culturally tailored diet and exercise intervention in the early post-transplant period [60].

Regarding a new regional kidney transplant service that is currently in development for North Queensland [61], participants made specific recommendations around building a safe and sustainable workforce. These included the need to secure required non-nephrology specialist services, recruitment of experienced clinicians to ensure provision of a non-inferior service, safe rotational rostering of on-call staff to prevent burn out, and the need for collaboration with established transplant services to provide support.

This study presents comprehensive insights from a diverse cross section of kidney transplant health professionals across Australia, including many different classes of remoteness and stages of professional experience. The investigators strived to recruit a representative sample to minimise any potential bias associated with the results and increases translatability of the findings. However, the proportion of support staff (such as social workers and Indigenous liaison officers) involved in direct transplant care that participated was relatively small, an outcome that has been seen across other similar studies [62] likely reflecting the identified workforce shortages in these areas. Similarly, participants based specifically in rural and remote areas also made up a small proportion of overall participants, likely a reflection of the hub-and-spoke model of transplant care provision [12] as well as workforce shortages in these areas, and also seen across other similar studies [62]. The inclusion of health professionals based only within Australia may reduce the transferability of the findings internationally, particularly for low- to middle-income countries or those with significant differences in health system structure or funding.

Conclusion

Kidney transplant health professionals described patient-specific and system level barriers to kidney transplantation for regional, rural, and remote populations in Australia that could be addressed or improved by the modification of current processes or implementation of new service delivery models for provision of transplant care. The findings of this study may support translation to changes in the provision of transplant care for this patient cohort at both a clinical practice and health policy

level, however further qualitative studies are also recommended to explore the perspectives of kidney transplant recipients.

Abbreviations

CKD	Chronic kidney disease
KF	Kidney failure
KRT	Kidney replacement therapy
MMM	Modified Monash Model
SRQR	Standards for Reporting Qualitative Research
LDKT	Living donor kidney transplantation
KDIGO	Kidney Disease Improving Global Outcomes
NIKTT	National Indigenous Kidney Transplantation Taskforce
QKTS	Queensland Kidney Transplant Service

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Author contributions

Research idea and study design: TKW, BDG, NSR, AJM; data collection: TKW; data analysis/interpretation: TKW, NSR; supervision and mentorship: BDG, NSR, AJM. Each author contributed important intellectual content during manuscript drafting or revision and agrees to be personally accountable for the individual's own contributions and to ensure that questions pertaining to the accuracy or integrity of any portion of the work, even one in which the author was not directly involved, are appropriately investigated and resolved, including with documentation in the literature if appropriate.

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Data availability

The datasets generated and analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Multisite ethics approval was granted by the Townsville Hospital and Health Service Human Research Ethics Committee (HREC/2023/QTHS/89342). Participants gave written informed consent. This study was conducted in accordance with the ethical principles of the Declaration of Helsinki.

Consent for publication

Not applicable.

Authors' information - consumer involvement

Co-author NSR has lived experience of both peritoneal dialysis and kidney transplantation and resides in a rural community. NSR has experience in qualitative research and contributed to this study's design, data analysis, manuscript preparation and supervision of the first authors' PhD candidature.

Competing interests

The authors declare no competing interests.

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