"Service providers' perspectives, attitudes and beliefs on health services delivery for Aboriginal people receiving haemodialysis in rural Australia"

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Service providers' perspectives, attitudes and beliefs on health services delivery for Aboriginal people receiving haemodialysis in rural Australia: A qualitative study

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ABSTRACT

Objective

Providing services to rural dwelling minority cultural groups with serious chronic disease is challenging due to access to care and cultural differences. This study aimed to describe service providers' perspectives on health services delivery for Aboriginal people receiving haemodialysis for end-stage kidney disease in rural Australia.

Design: Semi-structured interviews, thematic analysis

Setting: A health district in rural New South Wales, Australia

Participants: Using purposive sampling, 29 renal and allied service providers were recruited including: nephrologists, renal nurses, community nurses, Aboriginal health workers, social workers and managers. Six were Aboriginal and 23 non-Aboriginal.

Results:

Improving cultural understanding within the healthcare system was central to five themes identified: rigidity of service design (outreach, inevitable home treatment failures, pressure of system overload, limited efficacy of cultural awareness training, conflicting priorities in acute care); responding to social complexities (respecting but challenged by family obligations, assumptions about socioeconomic status, individualised care); promoting empowerment, trust and rapport (bridging gaps in cultural understanding, acknowledging relationship between land, people and environment, being time poor); distress at late diagnosis (lost opportunities, prioritise prevention); and contending with discrimination and racism (inherent judgement of lifestyle choices, inadequate cultural awareness, pervasive multi-level institutionalised racism, managing patient distrust).

Conclusions

Service providers believe current services are not designed to address cultural needs and Aboriginality, and that caring for Aboriginal patients receiving haemodialysis should be

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family-focussed and culturally safer. An Aboriginal specific pre-dialysis pathway, building staff cultural awareness and enhancing cultural safety within hospitals are recommended. Increasing patient support for home haemodialysis may improve health and quality of care outcomes.

Keywords

Aboriginal, cultural safety, end-stage kidney disease, haemodialysis, rural

Article summary

Article focus:

- To elicit clinician perspectives, beliefs and attitudes about working with Aboriginal haemodialysis recipients in rural Australia
- To identify strategies to improve experience, safety and treatment outcomes

Key messages:

- Service providers believe there needs to be cultural understanding at the systemic level to enable provision of flexible and culturally safer treatment and care for rural Aboriginal patients receiving haemodialysis
- Providing better access to home haemodialysis is suggested to keep families and communities intact in the Aboriginal community.
- Family-centred care for Aboriginal people with chronic kidney disease may improve health and quality of care outcomes

Strengths and limitations of this study:

- We elicited a broad range of views and experiences through purposive sampling.
- Our study included only service providers within a rural area of New South Wales, Australia

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INTRODUCTION

In Australia, the incidence of end-stage kidney disease (ESKD) is eight times that of non-Indigenous populations[1 2]. Haemodialysis (HD) is the most common life sustaining treatment for Aboriginal patients with ESKD. Health disparities, reluctance to engage with health services, miscommunication, and poorer treatment outcomes have been reported in Aboriginal people receiving HD[3 4].

Providing health services to minority cultural groups with chronic disease is challenging because of access and negotiating cultural differences[5 6]. In the Aboriginal population, further complications arise from past traumatic experiences when accessing mainstream health services[7 8]. The history of colonisation and the resulting trauma experienced has perpetuated distrust of western healthcare organisations[9]. Power imbalances and lack of understanding between service providers and Aboriginal patients still exist[10].

Healthcare providers working with Aboriginal people have a responsibility to ensure cultural safety. Shortfalls in cultural safety limit Aboriginal patients' ability to access information about their disease and treatment[11]. This can contribute to reduced treatment adherence and increased morbidity and mortality for people already suffering a heavier burden of chronic disease compared to non-Aboriginal Australians[12 13]. Lack of trust and rapport between clinicians and Aboriginal patients can result in patient disempowerment and suspicion towards healthcare services[14]. The attitudes of healthcare providers' shape how care is provided to patients and can influence health service design.

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This study describes service providers' perspectives on health services delivery for Aboriginal HD recipients in a rural region of NSW, Australia. A better understanding of this can inform strategies to promote cultural safety and improve quality of care.

METHODS

Participant selection and setting

Participants were recruited in a rural/regional location using a purposive selection strategy to increase diversity across health professionals from a range of disciplines, years of experience, age and gender. Participants were identified by consulting senior clinicians and Aboriginal health workers. There were 23 non-Aboriginal and 6 Aboriginal participants. Interviews were held at a time and place designated by participants. Ethical approval was obtained from the local health service and the University of Sydney. Written consent was obtained from all participants.

Data collection

Semi-structured face-to-face interviews were conducted with service providers involved in the care of rural Aboriginal patients receiving HD. The question guide was developed, informed by literature and discussion among the research team. To stimulate discussion, participants were asked to read three case studies that were adapted from interviews with Aboriginal clients of the services (Appendix A). Interviews were conducted between July and November 2012. On average, each interview lasted one hour and was facilitated by (E.R.), also a renal service provider who was known to most participants. Interviews were digitally recorded and transcribed. The interviews ceased when theoretical saturation was reached from concurrent analysis i.e. when no new concepts were arising.

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Analysis

The first author led the analysis documenting preliminary concepts. Transcripts were entered into NVivo 10 (™ QSR International) for coding, searching and organisation of qualitative data. Concepts were documented inductively, grouping similar or overlapping themes, patterns, relationships and common or divergent perspectives[15]. To enhance the analytical framework and ensure rigour, interpretation of the data and emergent themes were discussed with members of the research team. Member checking was conducted by inviting participants to meet and discuss the preliminary analysis. Participants confirmed the analysis and themes reflected their perspectives, attitudes and beliefs about service provision to Aboriginal people receiving HD.

RESULTS

Participant characteristics are provided in Table 1. Of the 31 invited, 29 (93%) consented to participate in the study, two were unable to participate due to clinical commitments. We identified five themes: rigidity of service design, promoting empowerment, trust and rapport, responding to social complexities, distress at late diagnosis, and contending with discrimination and racism. Table 2 provides quotations illustrating themes, and a thematic schema is provided in Figure 1.

Rigidity of service design:

Participants felt frustrated and powerless to improve Aboriginal patient's experience of HD due to constraints of current service design and delivery. They believed service design was

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too rigid for the diverse needs of Aboriginal people. They expressed a desire for policy makers to implement new flexible strategies for this client group.

Outreach

Most participants were aware of major logistical challenges for rural Aboriginal people accessing HD. Many believed poor transport arrangements restricted access and patients' ability to attend dialysis and the other frequent appointments renal patients require.

Inevitable home treatment failures

Although participants perceived home HD training to be done well and tailored to individual needs, they expressed concerns regarding lack of adequate home nursing support. They felt a single home visit after patients were sent home with their HD machine, with follow-up some months later was insufficient. Participants were concerned about the burden of care placed on patients' families. Some believed lack of home support was setting Aboriginal patients up to fail on home HD, perceiving reluctance by patients or families to ask for advice or help.

Pressure of system overload

Many believed renal services were increasingly over-stretched and under pressure, with insufficient resources to provide the support and culturally safe environments they felt were vital to Aboriginal patients. Some saw lack of time to spend with individuals as culturally disrespectful of Aboriginal patients. Some perceived that system overload limited their capacity to communicate with patients regarding their HD, or treatment problems.

Limited efficacy of cultural awareness training

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Some participants who had attended a one day cultural awareness training felt that it reinforced differences between Aboriginal and non-Aboriginal people in a negative way, providing insufficient education to counter stereotyping and commonly held assumptions. Others felt that regular, ongoing training could be more effective in addressing current shortfalls in non-Aboriginal staffs' cultural knowledge.

Conflicting priorities in acute care

The combination of chair based HD with acutely ill patients in the same setting was felt to be inappropriate. Participants perceived this as confronting, particularly for Aboriginal people, many of whom have seen family members die from ESKD. Clinicians who had to juggle the demands of acute clinical care and providing cultural safety for Aboriginal patients felt conflicted and confronted. Several participants reported they were seen by Aboriginal patients to lack cultural respect in acute settings and felt powerless to address this.

Responding to social complexities

Participants identified differences in their clinical interactions with Aboriginal patients compared with non-Aboriginal patients, acknowledging a need to adapt their communication styles. They perceived the need to support Aboriginal patients and address different and poorly understood social and cultural complexity and family obligations, which they believed influenced treatment adherence and health outcomes.

Respecting but challenged by family obligations

Many participants understood that patients experienced conflicts between family and treatment obligations, prioritising funerals and travel to family or cultural events above

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treatment. There was awareness of Aboriginal patients' connectedness to family and country that identified 'who' and 'what' they are. While they respected patients' priorities, they were uncertain about how to resolve the conflict between necessary treatment and patients' family commitments. They felt unable to help patients within a system they felt did not acknowledge the priority of family.

Assumptions about socioeconomic status

Some participants believed the financial burden placed on individuals impacted on treatment adherence for those on limited incomes. Sharing resources with family was culturally appropriate for Aboriginal patients which limited money for travel or to support treatment. Others however felt that it easy to stereotype Aboriginal clients, and warned that people should not make assumptions about socioeconomic status based on Aboriginality.

Individualised care

Participants believed that it was important to listen to the needs and concerns of patients in order to provide individualised care. To many this meant treating all patients as individuals, understanding their unique challenges, but emphasising the need to use simple and culturally appropriate language. They felt this was important in improving perceived shortfalls in Aboriginal patients' understanding of the complexity of their treatment regimens.

Promoting empowerment, trust and rapport

Building trust and rapport was believed to be vital when working with Aboriginal patients. Participants were aware that being on HD creates long term relationships between patients and clinicians, and acknowledged that when these relationships were not based on trust,

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disempowerment of patients often resulted. Most non-Aboriginal service providers acknowledged the need to build relationship before trust and rapport can develop. Aboriginal practitioners however stressed the need for a more family-focussed approach. They also believed non-Aboriginal health staff should be educated about the consequences of colonisation for Aboriginal people, and understand the damaging results of patients' past negative experiences with health services.

Bridging gaps in cultural understanding

Participants felt that a designated renal specific Aboriginal liaison or case manager, introduced at diagnosis could provide a cultural bridge between the patients, renal staff and services. They believed the role could encourage patients to better engage with their treatment and health services, by improving two way cultural understanding.

Acknowledging relationship between land, people and environment

Most participants were aware of Aboriginal peoples' relationships to family, land and the physical environment of the places they occupy. Many desired care models that deliver a culturally safer renal service to Aboriginal people, ideally in their homes. Some suggested that simple improvements to the environment of hospital renal units, by reconfiguring the physical layout could provide more comfortable spaces for Aboriginal people.

Being time poor

Participants working in renal units had limited time for effective communication with Aboriginal patients. They felt they lacked the ability to address the adverse effects of past traumas experienced within health services and the capacity to build Aboriginal people's trust and faith in their interactions within renal units. Some however believed that Aboriginal

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patients understood that nurses had busy workloads and would not feel ignored by their 'busyness'.

Inadequate screening and diagnosis

Lost opportunities

Frustration was expressed at poor access to screening in primary health care settings, delaying diagnosis. Participants were distressed by lost opportunities for slowing disease progression due to late diagnosis. Some stated that inclusion of family at diagnosis was a critical component in keeping patients engaged with pre-dialysis strategies to slow disease progression. Participants felt that if family members understood the purpose of pre-dialysis pathways, this may motivate them to encourage patients to participate and potentially avoid dialysis altogether. Providers believed that had impaired renal function been diagnosed earlier, premature deaths may be avoided and that early detection of CKD could prevent ESKD.

Prioritise prevention

Strong concerns were voiced about the need to educate Aboriginal people regarding their risk factors for kidney disease. Aboriginal participants and some non-Aboriginal participants stressed the importance of using family and Elders to pass on knowledge to younger generations. Some believed education strategies needed to be tailored to life experience and maturity, as these appeared to be seminal to Aboriginal peoples' understanding of their kidney disease. Others perceived that some patients would not learn until they were ready to hear about their disease.

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Contending with discrimination and racism

Some participants believed that individual racism was a problem, while others considered racism to be part of the Australian 'white' culture, defining it as historical suspicion of a person of another colour or cultural background. Most agreed racism was a barrier to effective communication and their ability to develop positive relationships with Aboriginal patients. A few participants mentioned that Aboriginal people could recognise "racist" body language which contributed to patients' distress and insecurities.

Inherent judgement of lifestyle choices

A minority of participants acknowledged that they sometimes made judgements about Aboriginal people's lifestyles, admitting ignorance of Aboriginal cultural values. They felt critical of Aboriginal people, who they perceived were unemployed and not helping themselves. Three of the 29 participants felt threatened by Aboriginal people and afraid of them in the clinical setting, fearing aggressive behaviour by patients when they did not understand or agree with treatment.

Inadequate cultural awareness compromising patient safety

Participants perceived insufficient cultural awareness of staff within hospitals which translated into lack of cultural safety for Aboriginal patients. The majority viewed Aboriginal patients as victims of individualised and institutionalised racism.

Pervasive multi-level institutionalised racism

Participants believed a health system that does not address the needs of minority cultural groups exhibited institutionalised racism. Some were distressed at the lack of an Aboriginal

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specific pre-dialysis pathway resulting in people not completing the programme. They were concerned that once diagnosed, Aboriginal people do not engage with pre-dialysis services until their crisis admission to hospital and an emergency initiation to dialysis.

Managing patient distrust

Participants were aware of Aboriginal peoples' fear of hospitalisation. Several stated that given the history of discrimination against Aboriginal people, they are surprised that patients actually sought 'western' medical intervention. Some related patients' stories they had heard from the past when children were taken from Aboriginal parents by welfare agencies if they attempted to access health services, or experiences of segregation and racism in hospitals. They believed that these experiences were still vividly implanted in Aboriginal people's memories, and patients still associated healthcare provision with trauma and discrimination.

> *"Whilst we encourage the system where people get home dialysis as much as possible instead of in-center, the system doesn't support Aboriginal clients to be managed in the home. There's issues about water quality, issues about care or support, about a range of factors which limit the uptake of home dialysis for Aboriginal people. So we put in people who, and I'm generalizing here, don't like to be inside for long periods of time into an environment that's very rigid, very procedurally based, and we sit them down in a chair for three to five hours. Um, that isn't culturally sensitive for any culture let alone any Aboriginal culture"* (Senior health services manager)

DISCUSSION

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Service providers caring for Aboriginal HD patients emphasised the importance of cultural safety and respect in promoting trust, rapport and patient empowerment. This involves cultural understanding and acknowledging the importance of patients' relationship to family and country. They recognised challenges such as racism, stereotyping, social complexities within Aboriginal families, inadequate cultural awareness training and conflicting priorities of providers, patients and health services delivery modes. Service providers urged for more advocacy and flexibility for Aboriginal patients receiving HD. Other studies have found culturally inappropriate healthcare, exposure to racism and poor communication[8 16 17] to be among barriers to care for Aboriginal people with chronic disease. This study however has identified that providing family-focussed care, improving cultural awareness training and Aboriginal specific care pathways and delivery could improve treatment, but also address Aboriginal people's historical distrust of mainstream health systems.

According to Taylor and Guerin, 'cultural safety is achieved when the recipients of care deem care to be meeting their cultural needs' [18]. Cultural safety involves examining institutional structures, acknowledging assumptions, addressing power imbalances between clinician and patients, and respecting Aboriginal cultural norms. Recent local work suggests that the current model of cultural awareness training for Australian health professionals requires improvement[11 19]. Cultural awareness training for healthcare providers should involve ongoing education about the priorities, values and preferences of Aboriginal patients as well as practical strategies to build trust and rapport within clinical settings.

Major barriers to access in rural areas included lack of transport to attend dialysis and frequent, multiple appointments associated with their treatment. Providing home HD was recommended by healthcare providers, but is currently limited by inadequate nursing staff.

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[20]. Home HD for remote Aboriginal patients is known to increase compliance and self-care when patients are given responsibility for their treatment, resulting in better quality of life and outcomes[21 22]. Additional in-home renal nurse support is suggested for sustaining home HD for Aboriginal patients and requires reassignment of resources and priorities. Avoidable acute care episodes and late diagnosis and management suggests urgent economic studies are needed to inform the costs of providing flexible, Aboriginal-focused care

Successful treatment of chronic disease for Aboriginal people requires community consultation, local knowledge and collaboration between mainstream services and Aboriginal controlled health services[16]. The vital role of family in Aboriginal culture was acknowledged by participants. Although they felt challenged by the social complexities relating to family, most agreed that Aboriginal peoples' connectedness to country and family is crucial to health and well-being. These connections are well known within Indigenous societies, where family obligations are frequently prioritized above the individual[23 24].

A family-centred philosophy for Indigenous people with chronic disease, rather than an individual-based patient-centred philosophy is recommended to address the relational nature of most Indigenous societies. The translation of knowledge down the generations by Aboriginal people, with the role of family and Elders in passing on important information about chronic disease is crucial[17]. Participants acknowledged the impact of previous trauma experienced by Aboriginal people when encountering health services. Family-centred care may play an important role in addressing this by empowering patients and families to communicate with service providers about achieving culturally appropriate care.

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Institutionalised racism was identified by healthcare providers in our study and is known to contribute to persistent health disparities in countries where Indigenous people have been colonised[25]. There is a need to provide treatment and care that addresses different belief systems[5 6]. Participants cited the lack of a separate Aboriginal engaged and led pre-dialysis pathway as an example of pervasive institutionalised racism. Devising a culturally appropriate pre-dialysis pathway, in conjunction with a renal specific Aboriginal advocate/support person, could provide a cultural bridge. This simple and affordable strategy may assist in reducing late diagnosis and crisis commencement onto HD, which is common for Aboriginal people[23] and known to increase morbidity and mortality[26]. This support role may also provide education and support for those caring for a family member facing ESKD and HD[4].

Healthcare providers believed that universal screening for CKD in Aboriginal people can slow disease progression and potentially avoid the need for HD[27]. Further, involving Elders and family in prevention strategies was deemed important, requiring more collaboration between renal services and Aboriginal controlled medical services, a trusted source for screening in Aboriginal communities.

Our study includes a range of healthcare providers involved in the care of Aboriginal HD recipients, making explicit many of the challenges and barriers in providing culturally safe and respectful care. However, there are some limitations. Data was collected from one rural locality therefore transferability to other areas may be limited.

CONCLUSION

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Service providers believe that cultural safety is fundamental in caring for Aboriginal people in rural renal services. This requires a better understanding among healthcare providers of the values and priorities of Aboriginal patients and building trust and rapport within mainstream services. Family-centred care, including better support for home haemodialysis, an Aboriginal specific pre-dialysis pathway and Aboriginal led community screening are likely to improve health and quality of care outcomes.

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Table 1. Participant characteristics

Characteristics	Interviewees (n)	(%)
Gender		
Male	11	(38)
Female	18	(62)
Aboriginality		
Aboriginal	6	(21)
Non-Aboriginal	23	(79)
Age (years)		
20-29	2	(7)
30-39	9	(1)
40-49	10	(34)
50-59	8	(28)
Role		
Senior Management/Policy	3	(10)
Nephrologist/VMOs	3	(10)
Hospital medical officer	1	(3)
Nurse Unit Manager	4	(14)
In-centre renal nurse	4	(14)
Home dialysis nurse	2	(7)
Community nurse/Nurse practitioner	4	(14)
Social worker	2	(7)
Aboriginal Health Worker	4	(14)
Aboriginal Liaison Officers	2	(7)

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Table 2. Illustrative quotations

Theme	Illustrative quotations
Rigidity of service design	
Outreach	Obviously transport's a huge issue and not necessarily something we can have an effect on. Its difficult because most clients don't actually live here in town yet this is the only centre that's available. (Female, 40s) One of the big things in particular is transport. . . In Queensland they use a bus… it travels all around and picks up everyone. (Male 30s) I would be aware that transport's probably the biggest issue for Aboriginal people accessing renal dialysis here' (Aboriginal male, 40s)
Inevitable home treatment failures	We need someone basically full time to be able to do home visits, home assessments, … but a lot of the time its hard, so if you've got people out in remote communities or towns. I mean it's so time consuming. (Male, 30s) It's culturally appropriate to stay at home but it's not culturally appropriate to put all that expectation on that person and on their family members … like a punitive approach when it's not maintained, to the point of being so unwell, being in hospital and it being a failure. (Female, 30s)
Pressure of system overload	The whole system is so busy and creaking all the time, . . . people lacking time to spend with them is often mistaken for cultural disrespect . . .we don't listen to people. We don't often identify what their needs are and we don't spend time identifying problems, sorting them through, explaining things to individuals.(Male, 50s) It's rush-rush-rush," let's get them on let's get them off". Um it doesn't matter which way you package that's what dialysis units are in an acute setting. ' (Female, 40s)
Limited efficacy of cultural awareness training	I don't believe you can do that as a one off because that's just a drop in the ocean, that's like saying "tick I've done that" and that's useless. There's got to be some sort of ongoing mechanism ongoing culture within the organization that supports that ethos constantly (Female, 30s) It's interesting I watched the reactions of the people in the group I was with and I think the people that left that day with no real joy are probably feeling more polarized and could identify the start of the day with that feeling as well. (Female 50s)
Conflicting priorities in acute care	It's hard that balance. When you're busy and clinical, and I've always found if you spent more time with the patients you get into getting an understanding of their stuff and you can usually work out a fairly acceptable relationship with the client. But there is often no time (Female 50s) Often the lack time that people have to spend with them is mistaken for lack of cultural disrespect and I think that the reality of it is the fact that we don't listen to people we don't often identify what their needs are and we don't spend time identifying problems, sorting them through, explaining things to individuals. (Male, 50s)
Responding to social complexities	
	'OK Societal disadvantage, you know that they are starting from a more difficult place than the majority of other white or you know non-Aboriginal renal patients. When you hear that someone is Aboriginal you know that there's a really good chance that they're going to more complicated from a social point of view, that they're going to need more support and will need more assistance in walking the walk through the whole gamut that comes with having to conform to a way of being that's going to be completely foreign to how they've been used to living their lives' (Female, 40s)
Respecting but challenged by patients' family obligations	They put funerals and family in front of their dialysis. It's like their health comes second and I understand that because that's part of their culture but I see the consequences of it. (Female, 40s) So they could actually do two days in a row and then miss a couple and if there was more flexibility in the days ….we find if there is any

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Theme	Illustrative quotations
	funeral or family obligations, they will miss their dialysis in preference to that (Female, 40s) That's one of the biggest roots of the difficulties for Aboriginal people with dialysis is that in their reality there is no true sense of self, but it' all about community. But our health system is dependent on self-confidentiality, privacy, um reliant on health literacy. Whereas the Indigenous culture is about community ownership (Female, 30s)
Making assumptions about patients' socioeconomic status	I think it's very easy to assume they all are going to be socio or economically and transport disadvantaged and that is not actually always true and it is a trap to fall into that assumption . . . every case will be different.' (Female, 50s) If they're a low social economic group whether they be Aboriginal or non-Aboriginal there's that element of similarity because of the financial and lack of education. But it comes back to the difference is there's probably more support and encouragement for a non-Aboriginal person to participate in those renal dialysis units.' (Aboriginal Male 40s)
Individualised care	Everyone is totally individual. I assess on that basis as time goes on for each patient, regardless of who they are. (Male, 30s) So, I think with supporting and just understanding and caring and being patient with the patients, because everyone's an individual and everyone's got different issues or feeling different about things at different stages' (Aboriginal female, 40s) 'I actually think those challenges as for non-Aboriginal people will be very much related to their individual backgrounds' (Female, 50s)
Promoting empowerment, trust and rapport	
Bridge gaps in cultural understanding	I would like to see more Aboriginal staff there . Even if it's apart from the hospital liaison person. But just someone there who they can relate to, who they can sit down and talk to, and who can relay their messages across to the non-Aboriginal staff. (Aboriginal female, 60s) They're a nice medium between the health service and their community …supporting vulnerable people and directing them, just basically giving them someone to go alongside the journey with them' (Female, 30s)
Acknowledging relationship between land, people and environment	For me it is understanding the intricate respect of land, of people, of the environment and all those things that makes us whole as an Aboriginal person that makes an Aboriginal person who they are. (Aboriginal male, 40s) You need big windows, no one facing each other so in that whole the physical setup and environment of those units are much more culturally aware or in tune. (Female, 50s)
Trust and rapport	I think there's is a bit an element of lack of understanding of the past policies that were in place where Aboriginal people were taken away from hospitals removed, the stolen generation and the grief and loss that associates with that.(Aboriginal male 40s) I guess that's where service providers need to understand that they need to build the relationship and the trust .They need to spend time with them and not just treat them as like a number. (Male, 40s)
Being time poor	'I doubt that it is that simple as the nurse is too busy to talk to, because I have had many Aboriginal patients say to me "my God you've had a busy shift you been flat out, you haven't had time to stop". They've got insight into that.' (Female, 50s) They feel that they're not listened to or that they don't get the time that they need because it's always such a rush to get everyone on (Female 40s)
Inadequate screening and diagnosis	
Lost opportunities	So we've got Aboriginal people dying of renal disease who don't even know and their GP's have not even made the diagnosis. And it may be that they're not going to GP'. (Female 50s) It has to go back to primary health care, I think. You've got to diagnose and prevent. (Female 40s)
Prioritise prevention	I mean there's more younger people getting kidney disease that I know of out in the communities but they're not doing anything about it.

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Theme	Illustrative quotations
	(Aboriginal female staff member, 60s) CKD screening was ruled out by the Department of Health two years ago. Not one health district been able to implement it in New South Wales because there are no resources allocated for it . . .So nobody's been able to implement it' (Female, 50s)
Contending with discrimination and racism	
	I think they do see discrimination. . .I think it comes from something that isn't just a system error. I think it is a community problem.' (Female 50s).
Inherent judgement of lifestyle choices	Sometimes I feel real empathy and compassion and understanding and some days it's just like "Get over it, go and get a job you lazy little ass". I've had to work, no one gives us a free ride. (Female, 40s)
Inadequate cultural awareness compromising patient safety	From a cultural awareness perspective I think we could all do with more cultural awareness in our workplaces' (Female, 30s))
Pervasive multi-level institutionalised racism	Once they are on that machine the system has failed and the system will have had many opportunities for interventions. So the challenge is actually to get effective reasonable pre- dialysis, pre-end stage care. (Female, 50s).
Managing patient distrust	They come with pre-perceived ideas. If people have had a bad experience in the past then that's it for everyone. (Female,40s)

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Details of contributors

All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Contributions

ER designed the study, conducted the interviews, transcribed interviews, carried out the thematic analysis and drafted the manuscript. LB contributed to the study design, participated in the thematic analysis and critical review and editing of the first and subsequent manuscript drafts. SW provided intellectual input, critical review and editing of first and subsequent manuscript drafts and assisted with thematic analysis. JS provided critical review and editing of the first and subsequent manuscript drafts and assisted with thematic analysis. AT contributed to the study design, participated in the thematic analysis and critical review of the first and subsequent manuscript drafts.

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Conflict of interest

No conflict of interest has been declared by the authors

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Figure 1. Thematic Schema

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Appendix A.

Interview Guide

Opening question

- In your experience of caring for Aboriginal renal patients, what are the major issues in managing their disease?
- How do you perceive that life changes for these patients once they commence haemodialysis?
- What do you tell Aboriginal patients about the positive aspects of receiving haemodialysis?
- What do you tell them about the negative aspects of receiving haemodialysis?
- Can you tell me about your experience of communicating with Aboriginal patients about their end stage kidney disease and haemodialysis treatment?
- What do you find the most difficult about communication with x on kidney disease; and dialysis?
- Have you found any particular strategies that have helped you when having to communicate difficult news or information about their health to Aboriginal patients?
- Have you experienced any specific instances of when you felt a patient was unable to understand what you said. And, was there a time when you felt a patient did not want to listen to what you said, why.
- Medications: What do you tell your Aboriginal patients about taking their medications? How do you encourage them to take their medications?

Closing question

- If you were advising a clinician about communicating with Aboriginal patients, what would be your three main suggestions / why?

Closing question

Is there something that you think might be important that we have not covered or is there something else that you want to mention?

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Case Study one

An Aboriginal man on haemodialysis in his mid 30s lives in a remote location with his family. He had tried living in town but found the Housing Department house he was allocated was in an area where there was significant conflict and the issues of the other residents impacted negatively on his family. He moved home to his community to be with his family support network. He has to travel 170 kms return to access his dialysis. Even though he cannulates himself and is self-caring within a renal unit, his wife is not confident to support him at home with dialysis. His children are too young to take on this responsibility. This man fears he is too far from help to have home dialysis and has reported that the ambulance takes too long to get to his community were he to have a problem. He is now faced with having to move back to town as the travel has become unaffordable and unsustainable.

Case study 2

A 54 year old Aboriginal woman is on haemodialysis and has significant problems with vascular surgery and access. Surgery leaves her with permanent nerve damage to one leg, resulting in high levels of pain requiring analgesia. She now has permanent loss of mobility and independence and has lost her driver's licence. This loss of independence is devastating for her and she is reliant on young family members and high doses of analgesia to function. There are significant transport issues for accessing dialysis at an in-centre renal unit. She reports ongoing problems at this unit with staff having what she considers limited cultural awareness. She says that "staff only tell me what to do" and feels they do not provide education or discuss her treatment with her. She also feels that staff avoid engaging with her and sees them spending time with other patients whilst not having conversations with her.

Case Study 3

A 60 year old Aboriginal man is having haemodialysis at home, after travelling three hours a day for three years to do in-centre dialysis. His niece is his carer, having been trained at the home training unit with him. This man however prioritises family commitments such as funerals and supporting others in need before his dialysis, resulting in irregular treatments. Despite this, he won't allow his niece to remove sufficient fluid during dialysis, and is regularly fluid overloaded. This triggers a series of acute hospital admissions and the patient finds himself once again forced to travel to have his weight stabilised. This becomes a pattern, with his niece unable to provide sufficient dialysis time and fluid removal to keep him out of hospital and in-centre dialysis.

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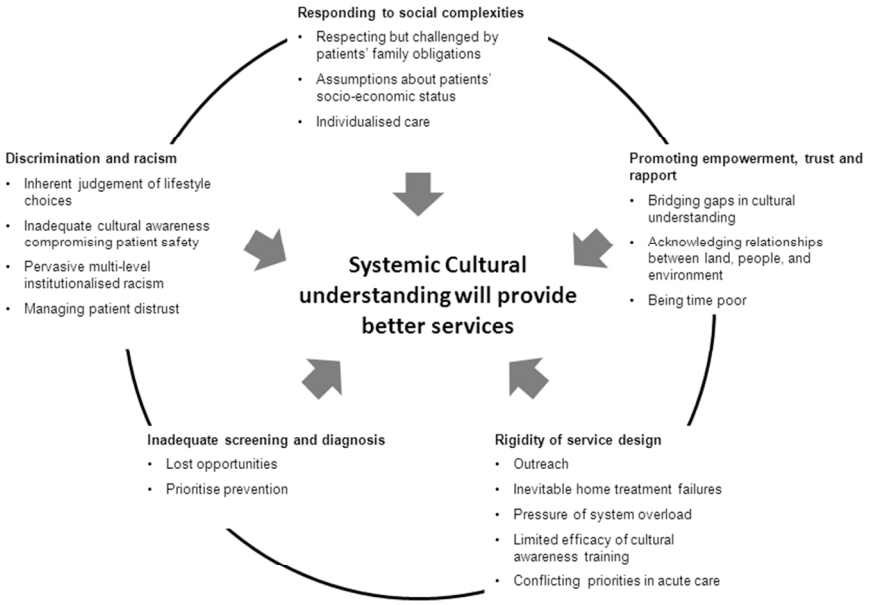

Figure 1. Thematic Schema
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Supplementary File. COREQ Checklist

No.	Item	Comment
Domain 1: Research team and reflexivity		
1	Interview/facilitator	ER
2	Credentials	ER (BN, Hons,), LB (PhD, AO), SW (PhD), JS (MPH, Dip ED.) AT (PhD, MPH, MM)
3	Occupation	ER (PhD candidate/Renal Nurse); LB (Head of School, Professor), SW (Sub-Dean, Early Career Researchers) JS (Ass. Professor, Indigenous Health) AT (Research Fellow)
4	Gender	ER, LB, JS, AT (Female)
5	Experience and training	ER has conducted qualitative research using a variety of methodologies, is a practicing renal nurse and PhD candidate with the University of Sydney
6	Relationship established	None
7	Participant knowledge of the interviewer	ER was known to some of the participants as a renal colleague and through professional interest in clinical and policy relevant issues in end-stage kidney disease.
8	Interviewer characteristics	ER is a social researcher and renal nurse with a focus in chronic disease and Indigenous health.
Study design		
9	Theoretical framework	Grounded theory
10	Sampling	Purposive
11	Method of approach	Face to face by
12	Sample size	Refer to Table 1
13	Non-participation	N=2 due to clinical commitments
14	Setting of data collection	Office or hospital meeting room
15	Presence of non-participants	None
16	Description of sample	Refer to Table 1
17	Interview guide	See Appendix
18	Repeat interviews	Single interview conducted
19	Audio/visual recording	Interviews were audio recorded
20	Field notes	ER recorded field notes
21	Duration	40 to 60 minutes
22	Data saturation	Yes
23	Transcripts returned	Yes
Analysis and findings		
24	Number of data coders	ER
25	Description of the coding tree	No
26	Derivation of themes	Inductively derived from data
27	Software	Nvivo
28	Participant checking	Yes
29	Quotations presented	Refer to Table 2
30	Data and findings consistent	Quotations provided to illustrate each theme.
31	Clarity of major themes	Yes
32	Clarity of minor themes	Yes

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"Service providers' perspectives, attitudes and beliefs on health services delivery for Aboriginal people receiving haemodialysis in rural Australia: A qualitative study"

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Service providers' perspectives, attitudes and beliefs on health services delivery for Aboriginal people receiving haemodialysis in rural Australia: A qualitative study

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ABSTRACT

Objective

Providing services to rural dwelling minority cultural groups with serious chronic disease is challenging due to access to care and cultural differences. This study aimed to describe service providers' perspectives on health services delivery for Aboriginal people receiving haemodialysis for end-stage kidney disease in rural Australia.

Design: Semi-structured interviews, thematic analysis

Setting: A health district in rural New South Wales, Australia

Participants: Using purposive sampling, 29 renal and allied service providers were recruited including: nephrologists, renal nurses, community nurses, Aboriginal health workers, social workers and managers. Six were Aboriginal and 23 non-Aboriginal.

Results:

Improving cultural understanding within the healthcare system was central to five themes identified: rigidity of service design (outreach, inevitable home treatment failures, pressure of system overload, limited efficacy of cultural awareness training, conflicting priorities in acute care); responding to social complexities (respecting but challenged by family obligations, assumptions about socioeconomic status, individualised care); promoting empowerment, trust and rapport (bridging gaps in cultural understanding, acknowledging relationship between land, people and environment, being time poor); distress at late diagnosis (lost opportunities, prioritise prevention); and contending with discrimination and racism (inherent judgement of lifestyle choices, inadequate cultural awareness, pervasive multi-level institutionalised racism, managing patient distrust).

Conclusions

Service providers believe current services are not designed to address cultural needs and Aboriginality, and that caring for Aboriginal patients receiving haemodialysis should be

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family-focussed and culturally safer. An Aboriginal specific pre-dialysis pathway, building staff cultural awareness and enhancing cultural safety within hospitals are recommended. Increasing patient support for home haemodialysis may improve health and quality of care outcomes.

Keywords

Aboriginal, cultural safety, end-stage kidney disease, haemodialysis, rural

Article summary

Article focus:

- To elicit clinician perspectives, beliefs and attitudes about working with Aboriginal haemodialysis recipients in rural Australia
- To identify strategies to improve experience, safety and treatment outcomes

Key messages:

- Service providers believe there needs to be cultural understanding at the systemic level to enable provision of flexible and culturally safer treatment and care for rural Aboriginal haemodialysis patients
- Additional renal nurse support is needed to enable Aboriginal people to access home haemodialysis, keeping families and communities intact.
- Patient-centred care should be replaced by family-centred care for Aboriginal people with serious chronic disease to improve health and quality of care outcomes

Strengths and limitations of this study:

- We actively sought a broad range of views and experiences through purposive sampling.
- Our study included only service providers within a rural area of New South Wales, Australia

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INTRODUCTION

In Australia, the incidence of end-stage kidney disease (ESKD) is eight times that of non-Indigenous populations[1,2].Haemodialysis (HD) is the most common life sustaining treatment for Aboriginal patients with ESKD. Health disparities, reluctance to engage with health services, miscommunication, and poorer treatment outcomes have been reported in Aboriginal people receiving HD[3,4]. Similar disparities and challenges exist for Indigenous peoples of other first world nations, for example Canada, New Zealand and the United States[2,5].

Australian Aboriginal people suffer higher levels of mortality and morbidity from kidney disease than non-Aboriginal Australians[6]. Diabetes is a leading contributor to ESKD and is a co-morbidity in the majority of patients, with frequent poor management of blood pressure and glycemic control also contributing factors[7,8]. Socio-economic disadvantage and late referral to a nephrologist are also known to increase morbidity and decrease survival time for ESKD patients[9,10].

Providing health services to minority cultural groups with chronic disease is challenging because of access and negotiating cultural differences[11,12]. In the Aboriginal population, further complications arise from past traumatic experiences when accessing mainstream health services[13,14]. The history of colonisation and the resulting trauma experienced has perpetuated distrust of western healthcare organisations[15]. Power imbalances and lack of understanding between service providers and Aboriginal patients still exist 16].

Healthcare providers working with Aboriginal people have a responsibility to ensure cultural safety. Shortfalls in cultural safety limit Aboriginal patients' ability to access information about their disease and treatment[17]. This can contribute to reduced treatment adherence and

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increased morbidity and mortality for people already suffering a heavier burden of chronic disease compared to non-Aboriginal Australians[18,19]. Lack of trust and rapport between clinicians and Aboriginal patients can result in patient disempowerment and suspicion towards healthcare services[20]. The attitudes of healthcare providers shape how care is provided to patients and can influence health service design.

This study describes service providers' perspectives on health services delivery for Aboriginal HD recipients in a rural region of NSW, Australia. A better understanding of this can inform strategies to promote cultural safety and improve quality of care.

METHODS

Participant selection and setting

Participants were recruited in a rural/regional location using a purposive selection strategy[21] to increase diversity across health professionals from a range of disciplines, years of experience, age and gender. Participants were identified by consulting senior clinicians and Aboriginal health workers. There were 23 non-Aboriginal and 6 Aboriginal participants. Disciplines included in the sample were: medical, nursing (renal, community and nurse practitioner), renal case managers, hospital management, health policy, social work, Aboriginal health workers and Aboriginal liaison officers. Interviews were held at a time and place designated by participants. Ethical approval was obtained from the local health service and the University of Sydney. Written consent was obtained from all participants.

Data collection

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Semi-structured face-to-face interviews were conducted with service providers involved in the care of rural Aboriginal patients receiving HD. The question guide was developed informed by literature and discussion among the research team. To stimulate discussion, participants were asked to read three case studies that were adapted from interviews with Aboriginal clients of the services (Appendix A). These were developed in consultation with senior clinicians and piloted on several renal nurses, who gave positive feedback on how these 'real life' scenarios enabled them to focus on the challenges facing their Aboriginal patients. Based on interviews with 18 rural Aboriginal patients on HD these case studies encompassed the key concerns identified by patients. Participants were asked to read the case studies prior to being interviewed. This helped to ensure that the interviews covered issues that were important to patients. This strategy was useful in eliciting participants' levels of cultural knowledge, attitudes and beliefs, based on 'real life' scenarios in a non-confronting manner. This approach accords with grounded theory where 'the entire research process is interactive…we bring past interactions and current interests into our research, and we interact with our empirical materials and emerging ideas'[22].

Interviews were conducted between July and November 2012. Each interview averaged one hour, facilitated by the lead author (E.R.). Interviews were digitally recorded and transcribed. Data analysis was conducted concurrently during data collection in accord with grounded theory methods[22]. Theoretical saturation[23] was reached at approximately 24 interviews, however with a total of 29 of 31 invitees responding and wanting to be participants, it was considered respectful and appropriate to interview all 29.

Analysis

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The first author led the analysis documenting preliminary concepts. Transcripts were entered into NVivo 10 (™ QSR International) for coding, searching and organisation of qualitative data. While not assuming to generate new theory with a relatively small circumscribed study in one location, the methods for this study were adapted from grounded theory. This was an appropriate methodology for beginning to develop relevant theory grounded in the participants' perspectives to inform health service delivery[21]. Concepts were documented inductively, grouping similar or overlapping themes, patterns, relationships and common or divergent perspectives[24]. This method followed Strauss's grounded theory 'coding paradigm', where theories are developed by interaction with the data. Coding moves from open (opening up the data to develop concepts) through to axial (the coding focuses around developing concepts) to selective coding (focussing on one category at a time). Explanations are discussed, reflected upon and built from dense coding[25].

To enhance the analytical framework and ensure rigour, interpretation of the data and emergent themes were discussed with members of the research team. Member checking was conducted by returning transcripts to participants to check for accuracy and inviting participants to meet and discuss the preliminary analysis. Participants confirmed the analysis and themes reflected their perspectives, attitudes and beliefs about service provision to Aboriginal people receiving HD. Validity and accuracy of the data analysis was thus enhanced by seeking multiple perspectives (i.e. triangulation) including: patient perspectives gained from a reference group of Aboriginal renal patients and Elders who guided the study; confirmation by discussions with participants; and involving multiple researchers from different disciplines in the analysis[26]. The first author used self-reflexivity to check for potential biases from her dual clinician/researcher role, that may have influenced decision making throughout the study[26,27].

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RESULTS

Participant characteristics are provided in Table 1. Of the 31 invited, 29 (93%) consented to participate in the study, two were unable to participate due to clinical commitments. We identified five themes: rigidity of service design, promoting empowerment, trust and rapport, responding to social complexities, distress at late diagnosis, and contending with discrimination and racism. Table 2 provides quotations illustrating themes, and a thematic schema is provided in Figure 1.

Rigidity of service design:

Participants felt frustrated and powerless to improve Aboriginal patient's experience of HD due to constraints of current service design and delivery. They believed service design was too rigid for the diverse needs of Aboriginal people. They expressed a desire for policy makers to implement new flexible strategies for this client group.

Transport and access Most participants were aware of major logistical challenges for rural Aboriginal people accessing HD. Many believed poor transport arrangements restricted access and patients' ability to attend dialysis and the other frequent appointments renal patients require. Participants described many instances of Aboriginal patients' negative outcomes resulting from poor access, for example: inability to attend podiatry appointments resulting in reduced or loss of mobility.

Inevitable home treatment failures

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Although participants perceived home HD training to be done well and tailored to individual needs, they expressed concerns regarding lack of adequate home nursing support. They felt a single home visit after patients were sent home with their HD machine, with follow-up some months later was insufficient. Participants were concerned about the burden of care placed on patients' families. Some believed lack of home support was setting Aboriginal patients up to fail on home HD, perceiving reluctance by patients or families to ask for advice or help.

Pressure of system overload

Many believed renal services were increasingly over-stretched and under pressure, with insufficient resources to provide the support and culturally safe environments they felt were vital to Aboriginal patients. Some saw lack of time to spend with individuals as culturally disrespectful of Aboriginal patients. Some perceived that system overload limited their capacity to communicate with patients regarding their HD, or treatment problems.

Limited efficacy of cultural awareness training

Some participants who had attended the one day cultural awareness training felt that it reinforced differences between Aboriginal and non-Aboriginal people in a negative way, providing insufficient education to counter stereotyping and commonly held assumptions. Others felt that regular, ongoing training could be more effective in addressing current shortfalls in non-Aboriginal staffs' cultural knowledge. Aboriginal cultural awareness training is deemed mandatory for healthcare professionals within this health service, however the majority of participants reported they had not been given the opportunity to attend the one day session. While this training was deemed 'mandatory' most participants believed there were inadequate resources for sufficient training places or to backfill clinical staff to attend.

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Conflicting priorities in acute care

The combination of chair based HD with acutely ill patients in the same setting was felt to be inappropriate. Participants perceived this as confronting, particularly for Aboriginal people, many of whom have seen family members die from ESKD. Clinicians who had to juggle the demands of acute clinical care and providing cultural safety for Aboriginal patients felt conflicted and confronted. Several participants reported they were seen by Aboriginal patients to lack cultural respect in acute settings and felt powerless to address this.

Responding to social complexities

Participants identified differences in their clinical interactions with Aboriginal patients compared with non-Aboriginal patients, acknowledging a need to adapt their communication styles. They perceived the need to support Aboriginal patients and address different and poorly understood social and cultural complexity and family obligations, which they believed influenced treatment adherence and health outcomes.

Respecting but challenged by family obligations

Many participants understood that patients experienced conflicts between family and treatment obligations, prioritising funerals and travel to family or cultural events above treatment. There was awareness of Aboriginal patients' connectedness to family and country that identified 'who' and 'what' they are. While they respected patients' priorities, they were uncertain about how to resolve the conflict between necessary treatment and patients' family commitments. They felt unable to help patients within a system they felt did not acknowledge the priority of family.

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Assumptions about socioeconomic status

Some participants believed the financial burden placed on individuals impacted on treatment adherence for those on limited incomes. Sharing resources with family was culturally appropriate for Aboriginal patients which limited money for travel or to support treatment. Others however felt that it easy to stereotype Aboriginal clients, and warned that people should not make assumptions about socioeconomic status based on Aboriginality.

Individualised care

Participants believed that it was important to listen to the needs and concerns of patients in order to provide individualised care. To many this meant treating all patients as individuals, understanding their unique challenges, but emphasising the need to use simple and culturally appropriate language. They felt this was important in improving perceived shortfalls in Aboriginal patients' understanding of the complexity of their treatment regimens.

Promoting empowerment, trust and rapport

Building trust and rapport was believed to be vital when working with Aboriginal patients. Participants were aware that being on HD creates long term relationships between patients and clinicians, and acknowledged that when these relationships were not based on trust, disempowerment of patients often resulted. Most non-Aboriginal service providers acknowledged the need to build relationships before trust and rapport can develop. Aboriginal practitioners however stressed the need for a more family-focussed approach. They also believed non-Aboriginal health staff should be educated about the consequences of colonisation for Aboriginal people, and understand the damaging results of patients' past negative experiences with health services.

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Bridging gaps in cultural understanding

Participants felt that a designated renal specific Aboriginal liaison or case manager, introduced at diagnosis could provide a cultural bridge between the patients, renal staff and services. They believed the role could encourage patients to better engage with their treatment and health services, by improving two way cultural understanding.

Acknowledging relationship between land, people and environment

Most participants were aware of Aboriginal peoples' relationships to family, land and the physical environment of the places they occupy. Many desired care models that deliver a culturally safer renal service to Aboriginal people, ideally in their homes. Some suggested that simple improvements to the environment of hospital renal units, by reconfiguring the physical layout could provide more comfortable spaces for Aboriginal people.

Being time poor

Participants working in renal units had limited time for effective communication with Aboriginal patients. They felt they lacked the ability to address the adverse effects of past traumas experienced within health services and the capacity to build Aboriginal people's trust and faith in their interactions within renal units. Some however believed that Aboriginal patients understood that nurses had busy workloads and would not feel ignored by their 'busyness'.

Inadequate screening and diagnosis

The majority of participants voiced their awareness of Aboriginal people frequently being diagnosed late in the progression of their disease. Aboriginal informants working with renal

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patients and several non-Aboriginal participants felt that this was due to Aboriginal people's inherent mistrust of mainstream health services. There were also comments about many Aboriginal people having had family members pass away or experience high levels of trauma, resulting in their avoidance of screening from fear of being diagnosed with kidney disease themselves.

Lost opportunities

Frustration was expressed at poor access to screening in primary health care settings, delaying diagnosis. Participants were distressed by lost opportunities for slowing disease progression due to late diagnosis. Some stated that inclusion of family at diagnosis was a critical component in keeping patients engaged with pre-dialysis strategies to slow disease progression. Participants felt that if family members understood the purpose of pre-dialysis pathways, this may motivate them to encourage patients to participate and potentially avoid dialysis altogether. Providers believed that had impaired renal function been diagnosed earlier, premature deaths may be avoided and that early detection of CKD could prevent ESKD.

Prioritise prevention

Strong concerns were voiced about the need to educate Aboriginal people regarding their risk factors for kidney disease. Aboriginal participants and some non-Aboriginal participants stressed the importance of using family and Elders to pass on knowledge to younger generations. Some believed education strategies needed to be tailored to life experience and maturity, as these appeared to be seminal to Aboriginal peoples' understanding of their kidney disease. Others perceived that some patients would not learn until they were ready to hear about their disease.

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Contending with discrimination and racism

Some participants believed that individual racism was a problem, while others considered racism to be part of the Australian 'white' culture, defining it as historical suspicion of a person of another colour or cultural background. Most agreed racism was a barrier to effective communication and their ability to develop positive relationships with Aboriginal patients. A few participants mentioned that Aboriginal people could recognise "racist" body language which contributed to patients' distress and insecurities.

Inherent judgement of lifestyle choices

A minority of participants acknowledged that they sometimes made judgements about Aboriginal people's lifestyles, admitting ignorance of Aboriginal cultural values. They felt critical of Aboriginal people, who they perceived were unemployed and not helping themselves. Three of the 29 participants felt threatened by Aboriginal people and afraid of them in the clinical setting, fearing aggressive behaviour by patients when they did not understand or agree with treatment.

Inadequate cultural awareness compromising patient safety

Participants perceived insufficient cultural awareness of staff within hospitals which translated into lack of cultural safety for Aboriginal patients. The majority viewed Aboriginal patients as victims of individualised and institutionalised racism.

Pervasive multi-level institutionalised racism

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Participants believed a health system that does not address the needs of minority cultural groups exhibited institutionalised racism. Some were distressed at the lack of an Aboriginal specific pre-dialysis pathway resulting in people not completing the programme. They were concerned that once diagnosed, Aboriginal people do not engage with pre-dialysis services until their crisis admission to hospital and an emergency initiation to dialysis.

Managing patient distrust

Participants were aware of Aboriginal peoples' fear of hospitalisation. Several stated that given the history of discrimination against Aboriginal people, they are surprised that patients actually sought 'western' medical intervention. Some related patients' stories they had heard from the past when children were taken from Aboriginal parents by welfare agencies if they attempted to access health services, or experiences of segregation and racism in hospitals. They believed that these experiences were still vividly implanted in Aboriginal people's memories, and patients still associated healthcare provision with trauma and discrimination.

Interrelation of themes

The five themes link together under the overarching theme of 'Systemic cultural understanding will provide better services' (Figure 1.). Each theme relates to this major theme, with most participants acknowledging that there is a systemic lack of cultural safety impacting on service delivery and health outcomes for rural Aboriginal renal patients. A basic mistrust of mainstream services is a barrier to early screening and detection. When eventually detected, issues of transport and access to community renal nurses make it difficult to keep people at home once they commence HD. When patients are forced to travel to in-centre HD, inadequate cultural awareness of staff and perceptions of pervasive

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institutionalised racism compound to make hospital based treatment culturally unsafe for Aboriginal people.

DISCUSSION

Service providers caring for Aboriginal HD patients emphasised the importance of cultural safety and respect in promoting trust, rapport and patient empowerment. This involves cultural understanding and acknowledging the importance of patients' relationship to family and country. They recognised challenges such as racism, stereotyping, social complexities within Aboriginal families, inadequate cultural awareness training and conflicting priorities of providers, patients and health services delivery modes. Service providers urged for more advocacy and flexibility for Aboriginal patients receiving HD.

Studies in remote and metropolitan settings have found that lack of cultural safety and access issues have major implications for the well-being of Aboriginal renal patients[4,28-30]. This paper reports similar challenges for rural dwelling renal patients, recommending strategies to address these. A 2010 study in remote Australia demonstrated that provision of culturally appropriate services, provided by an Aboriginal controlled medical service has resulted in Aboriginal HD outcomes being comparable with those of non-Aboriginal Australians[31]. Other studies have found culturally inappropriate healthcare, exposure to racism and poor communication[14,32,33] to be among barriers to care for Aboriginal people with chronic disease. This study however has identified that providing family-focussed care, improving cultural awareness training and Aboriginal specific care pathways and delivery could

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improve treatment, but also address Aboriginal people's historical distrust of mainstream health systems.

According to Taylor and Guerin, 'cultural safety is achieved when the recipients of care deem care to be meeting their cultural needs'[34]. Cultural safety involves examining institutional structures, acknowledging assumptions, addressing power imbalances between clinician and patients, and respecting Aboriginal cultural norms. Recent local work suggests that the current model of cultural awareness training for Australian health professionals requires improvement[17,35]. Cultural awareness training for healthcare providers should involve ongoing education about the priorities, values and preferences of Aboriginal patients as well as practical strategies to build trust and rapport within clinical settings.

Major barriers to access in rural areas included lack of transport to attend dialysis and frequent, multiple appointments associated with their treatment. Providing home HD was recommended by healthcare providers, but is currently limited by inadequate nursing staff[36]. Home HD for remote Aboriginal patients is known to increase compliance and self-care when patients are given responsibility for their treatment, resulting in better quality of life and outcomes[37,38]. Additional in-home renal nurse support is suggested for sustaining home HD for Aboriginal patients and requires reassignment of resources and priorities. Avoidable acute care episodes and late diagnosis and management suggests urgent economic studies are needed to inform the costs of providing flexible, Aboriginal-focused care.

Successful treatment of chronic disease for Aboriginal people requires community consultation, local knowledge and collaboration between mainstream services and Aboriginal

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controlled health services[32]. The vital role of family in Aboriginal culture was acknowledged by participants. Although they felt challenged by the social complexities relating to family, most agreed that Aboriginal peoples' connectedness to country and family is crucial to health and well-being. These connections are well known within Indigenous societies, where family obligations are frequently prioritized above the individual[39,40].

A family-centred philosophy for Indigenous people with chronic disease, rather than an individual-based patient-centred philosophy is recommended to address the relational nature of most Indigenous societies. The translation of knowledge down the generations by Aboriginal people, with the role of family and Elders in passing on important information about chronic disease is crucial [33]. Participants acknowledged the impact of previous trauma experienced by Aboriginal people when encountering health services. Family-centred care may play an important role in addressing this by empowering patients and families to communicate with service providers about achieving culturally appropriate care.

Institutionalised racism was identified by healthcare providers in our study and is known to contribute to persistent health disparities in countries where Indigenous people have been colonised[41]. There is a need to provide treatment and care that addresses different belief systems[11,12]. Participants cited the lack of a separate Aboriginal engaged and led pre-dialysis pathway as an example of pervasive institutionalised racism. Devising a culturally appropriate pre-dialysis pathway, in conjunction with a renal specific Aboriginal advocate/support person, could provide a cultural bridge. This simple and affordable strategy may assist in reducing late diagnosis and crisis commencement onto HD, which is common for Aboriginal people [39] and known to increase morbidity and mortality [9]. This support

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role may also provide education and support for those caring for a family member facing ESKD and HD[4].

Healthcare providers believed that universal screening for CKD in Aboriginal people can slow disease progression and potentially avoid the need for HD[42]. Further, involving Elders and family in prevention strategies was deemed important, requiring more collaboration between renal services and Aboriginal controlled medical services, a trusted source for screening in Aboriginal communities.

Our study includes a range of healthcare providers involved in the care of Aboriginal HD recipients, making explicit many of the challenges and barriers in providing culturally safe and respectful care. However, there are some limitations. Data was collected from one rural locality therefore transferability to other areas may be limited. We would however argue that our use of purposive sampling gave considerable strength to this study by including a diverse and broad range of perspectives and experience, therefore increasing the potential for transferability of findings and recommendations for service delivery to Aboriginal people experiencing renal disease in other rural communities[43]. This study has focussed on services for Aboriginal people on HD only and not included peritoneal dialysis (PD) because there were no Aboriginal patients receiving PD in the rural region at the time of this study. Further research exploring service delivery for Aboriginal people receiving PD is recommended.

Conclusion

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Service providers believe current services are not designed to address cultural needs and Aboriginality, and that caring for Aboriginal patients receiving haemodialysis should be family-focussed and culturally safer. Prioritising prevention by increased screening and education about kidney disease is paramount. An Aboriginal specific pre-dialysis pathway, building staff cultural awareness and enhancing cultural safety within hospitals are recommended. Increasing patient support for home haemodialysis may improve health and quality of care outcomes. Implementing the recommendations from this study may also help in addressing patient mistrust of mainstream health services and reduce the impact of institutionalised racism on Aboriginal renal patients

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Table 1. Participant characteristics

Characteristics	Interviewees (n)	(%)
Gender		
Male	11	(38)
Female	18	(62)
Aboriginal	6	(21)
Non-Aboriginal	23	(79)
Years of experience working with Aboriginal renal patients		
<5	2	(7)
6-10	9	(31)
11-20	11	(38)
>20	7	(24)
Role		
Senior Management/Policy	3	(10)
Nephrologist/VMOs	3	(10)
Hospital medical officer	1	(3)
Nurse Unit Manager	4	(14)
In-centre renal nurse	4	(14)
Home dialysis nurse	2	(7)
Community nurse/Nurse practitioner	4	(14)
Social worker	2	(7)
Aboriginal Health Worker	4	(14)
Aboriginal Liaison Officers	2	(7)

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Table 2. Participant quotes table

Theme	Illustrative quotations
Rigidity of service design	
Outreach	Obviously transport's a huge issue and not necessarily something we can have an effect on. Its difficult because most clients don't actually live here in town yet this is the only centre that's available. (Female, 40s)
	One of the big things in particular is transport. . . In Queensland they use a bus… it travels all around and picks up everyone. (Male 30s)
	I would be aware that transport's probably the biggest issue for Aboriginal people accessing renal dialysis here' (Aboriginal male, 40s)
Inevitable home treatment failures	We need someone basically full time to be able to do home visits, home assessments, … but a lot of the time its hard, so if you've got people out in remote communities or towns. I mean it's so time consuming. (Male, 30s)
	I think that people going on home haemodialysis need extra support, and I can absolutely feel for the home haemo staff because you're cutting an umbilical cord and then you just sit and wait because you know they're gonna come back no matter who they are. (Female, 30s)
	It's culturally appropriate to stay at home but it's not culturally appropriate to put all that expectation on that person and on their family members … like a punitive approach when it's not maintained, to the point of being so unwell, being in hospital and it being a failure. (Female, 30s)
Pressure of system overload	The whole system is so busy and creaking all the time, . . . people lacking time to spend with them is often mistaken for cultural disrespect . . .we don't listen to people. We don't often identify what their needs are and we don't spend time identifying problems, sorting them through, explaining things to individuals.(Male, 50s)
	It's rush-rush-rush," let's get them on let's get them off". Um it doesn't matter which way you package that's what dialysis units are in an acute setting. ' (Female, 40s)
Limited efficacy of cultural awareness training	I don't believe you can do that as a one off because that's just a drop in the ocean, that's like saying "tick I've done that" and that's useless. There's got to be some sort of ongoing mechanism ongoing culture within the organization that supports that ethos constantly (Female, 30s)
	It's interesting I watched the reactions of the people in the group I was with and I think the people that left that day with no real joy are probably feeling more polarized and could identify the start of the day with that feeling as well. (Female 50s)
Conflicting priorities in acute care	It's hard that balance. When you're busy and clinical, and I've always found if you spent more time with the patients you get into getting an understanding of their stuff and you can usually work out a fairly acceptable relationship with the client. But there is often no time (Female 50s)
	Often the lack time that people have to spend with them is mistaken for lack of cultural disrespect and I think that the reality of it is the fact that we don't listen to people we don't often identify what their needs are and we don't spend time identifying problems, sorting them through, explaining things to individuals. (Male, 50s)
Responding to social complexities	
	'OK Societal disadvantage, you know that they are starting from a more difficult place than the majority of other white or you know non-Aboriginal renal patients. When you hear that someone is Aboriginal you know that there's a really good chance that they're going to more complicated from a social point of view, that they're going to need more support and will need more assistance in walking the walk through the whole gamut that comes with having to conform to a way of being that's going to be completely foreign to how they've been used to living their lives' (Female, 40s)
Respecting but challenged by patients' family obligations	They put funerals and family in front of their dialysis. It's like their health comes second and I understand that because that's part of their culture but I see the consequences of it. (Female, 40s)
	So they could actually do two days in a row and then miss a couple and if there was

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Theme	Illustrative quotations
	more flexibility in the days ….we find if there is any funeral or family obligations, they will miss their dialysis in preference to that (Female, 40s)
	That's one of the biggest roots of the difficulties for Aboriginal people with dialysis is that in their reality there is no true sense of self, but it' all about community. But our health system is dependent on self-confidentiality, privacy, um reliant on health literacy. Whereas the Indigenous culture is about community ownership (Female, 30s)
Making assumptions about patients' socioeconomic status	I think it's very easy to assume they all are going to be socio or economically and transport disadvantaged and that is not actually always true and it is a trap to fall into that assumption . . . every case will be different.' (Female, 50s)
	If they're a low social economic group whether they be Aboriginal or non-Aboriginal there's that element of similarity because of the financial and lack of education. But it comes back to the difference is there's probably more support and encouragement for a non-Aboriginal person to participate in those renal dialysis units.' (Aboriginal Male 40s)
Individualised care	Everyone is totally individual. I assess on that basis as time goes on for each patient, regardless of who they are. (Male, 30s)
	So, I think with supporting and just understanding and caring and being patient with the patients, because everyone's an individual and everyone's got different issues or feeling different about things at different stages' (Aboriginal female, 40s)
	'I actually think those challenges as for non-Aboriginal people will be very much related to their individual backgrounds' (Female, 50s)
Promoting empowerment, trust and rapport	
Bridge gaps in cultural understanding	I would like to see more Aboriginal staff there . Even if it's apart from the hospital liaison person. But just someone there who they can relate to, who they can sit down and talk to, and who can relay their messages across to the non-Aboriginal staff. (Aboriginal female, 60s)
	They're a nice medium between the health service and their community …supporting vulnerable people and directing them, just basically giving them someone to go alongside the journey with them' (Female, 30s)
Acknowledging relationship between land, people and environment	For me it is understanding the intricate respect of land, of people, of the environment and all those things that makes us whole as an Aboriginal person that makes an Aboriginal person who they are. (Aboriginal male, 40s)
	You need big windows, no one facing each other so in that whole the physical setup and environment of those units are much more culturally aware or in tune. (Female, 50s)
Trust and rapport	I think there's is a bit an element of lack of understanding of the past policies that were in place where Aboriginal people were taken away from hospitals removed, the stolen generation and the grief and loss that associates with that.(Aboriginal male 40s)
	I guess that's where service providers need to understand that they need to build the relationship and the trust .They need to spend time with them and not just treat them as like a number. (Male, 40s)
Being time poor	'I doubt that it is that simple as the nurse is too busy to talk to, because I have had many Aboriginal patients say to me "my God you've had a busy shift you been flat out, you haven't had time to stop". They've got insight into that.' (Female, 50s)
	They feel that they're not listened to or that they don't get the time that they need because it's always such a rush to get everyone on (Female 40s)
Inadequate screening and diagnosis	
Lost opportunities	So we've got Aboriginal people dying of renal disease who don't even know and their GP's have not even made the diagnosis. And it may be that they're not going to GP'. (Female 50s)
	it has to go back to primary health care, I think. You've got to diagnose and prevent. (Female 40s)'
Prioritise prevention	I mean there's more younger people getting kidney disease that I know of out in the communities but they're not doing anything about it. (Aboriginal female staff member, 60s)
	CKD screening was ruled out by the Department of Health two years ago. Not one

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Theme	Illustrative quotations
	health district been able to implement it in New South Wales because there are no resources allocated for it . . .So nobody's been able to implement it' (Female, 50s)
Contending with discrimination and racism	
	I think they do see discrimination. . .I think it comes from something that isn't just a system error. I think it is a community problem.' (Female 50s).
Inherent judgement of lifestyle choices	Sometimes I feel real empathy and compassion and understanding and some days it's just like "Get over it, go and get a job you lazy little ass". I've had to work, no one gives us a free ride. (Female, 40s)
Inadequate cultural awareness compromising patient safety	From a cultural awareness perspective I think we could all do with more cultural awareness in our workplaces' (Female, 30s))
Pervasive multi-level institutionalised racism	Once they are on that machine the system has failed and the system will have had many opportunities for interventions. So the challenge is actually to get effective reasonable pre- dialysis, pre-end stage care. (Female, 50s).
Managing patient distrust	They come with pre-perceived ideas. If people have had a bad experience in the past then that's it for everyone. (Female,40s)

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Conflict of interest

No conflict of interest has been declared by the authors

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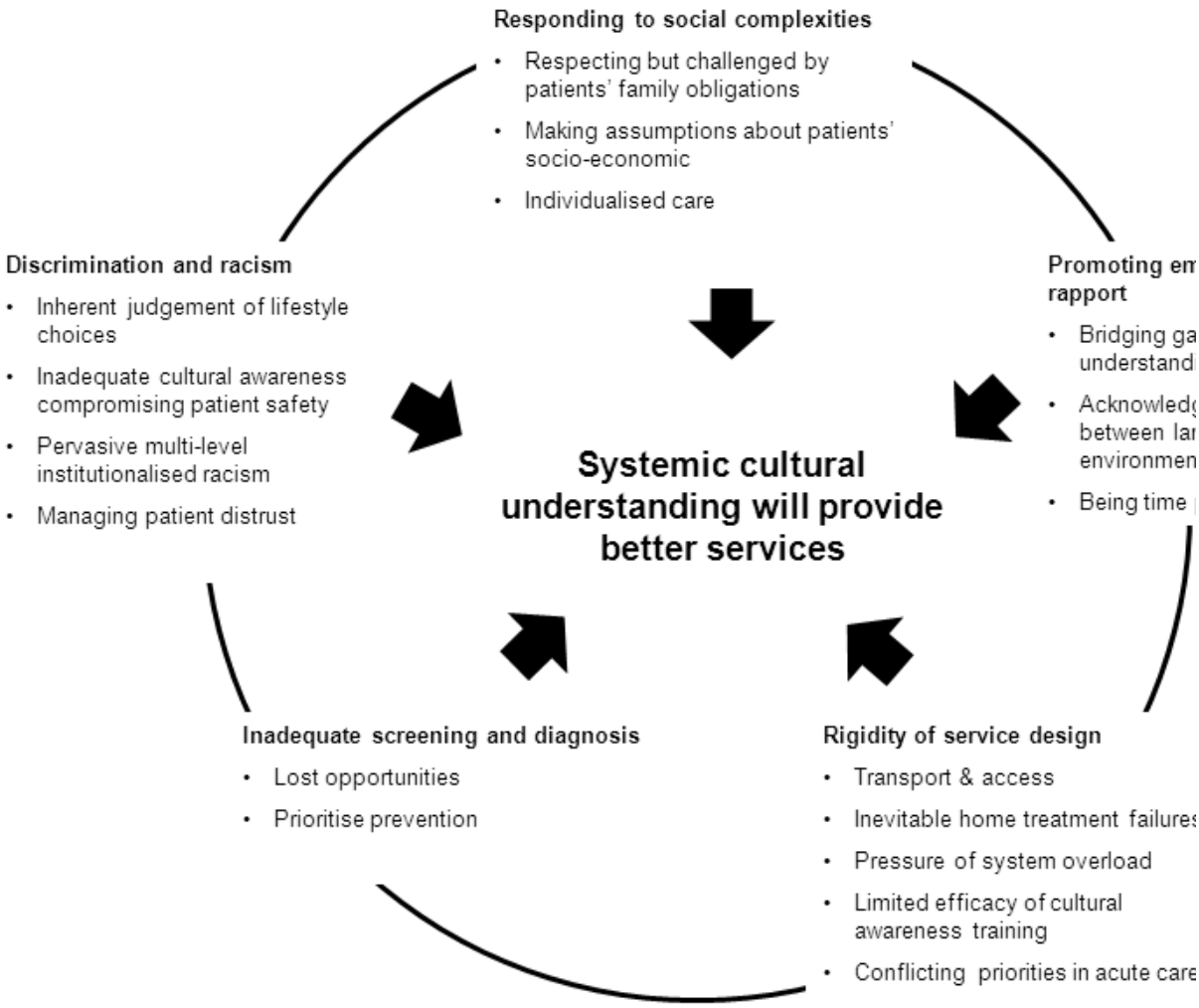
Figure 1. Thematic Schema



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Appendix A.

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Case Study one

An Aboriginal man on haemodialysis in his mid 30s lives in a remote location with his family. He had tried living in town but found the Housing Department house he was allocated was in an area where there was significant conflict and the issues of the other residents impacted negatively on his family. He moved home to his community to be with his family support network. He has to travel 170 kms return to access his dialysis. Even though he cannulates himself and is self-caring within a renal unit, his wife is not confident to support him at home with dialysis. His children are too young to take on this responsibility. This man fears he is too far from help to have home dialysis and has reported that the ambulance takes too long to get to his community were he to have a problem. He is now faced with having to move back to town as the travel has become unaffordable and unsustainable.

Case study 2

A 54 year old Aboriginal woman is on haemodialysis and has significant problems with vascular surgery and access. Surgery leaves her with permanent nerve damage to one leg, resulting in high levels of pain requiring analgesia. She now has permanent loss of mobility and independence and has lost her driver's licence. This loss of independence is devastating for her and she is reliant on young family members and high doses of analgesia to function. There are significant transport issues for accessing dialysis at an in-centre renal unit. She reports ongoing problems at this unit with staff having what she considers limited cultural awareness. She says that "staff only tell me what to do" and feels they do not provide education or discuss her treatment with her. She also feels that staff avoid engaging with her and sees them spending time with other patients whilst not having conversations with her.

Case Study 3

A 60 year old Aboriginal man is having haemodialysis at home, after travelling three hours a day for three years to do in-centre dialysis. His niece is his carer, having been trained at the home training unit with him. This man however prioritises family commitments such as funerals and supporting others in need before his dialysis, resulting in irregular treatments. Despite this, he won't allow his niece to remove sufficient fluid during dialysis, and is regularly fluid overloaded. This triggers a series of acute hospital admissions and the patient finds himself once again forced to travel to have his weight stabilised. This becomes a pattern, with his niece unable to provide sufficient dialysis time and fluid removal to keep him out of hospital and in-centre dialysis.

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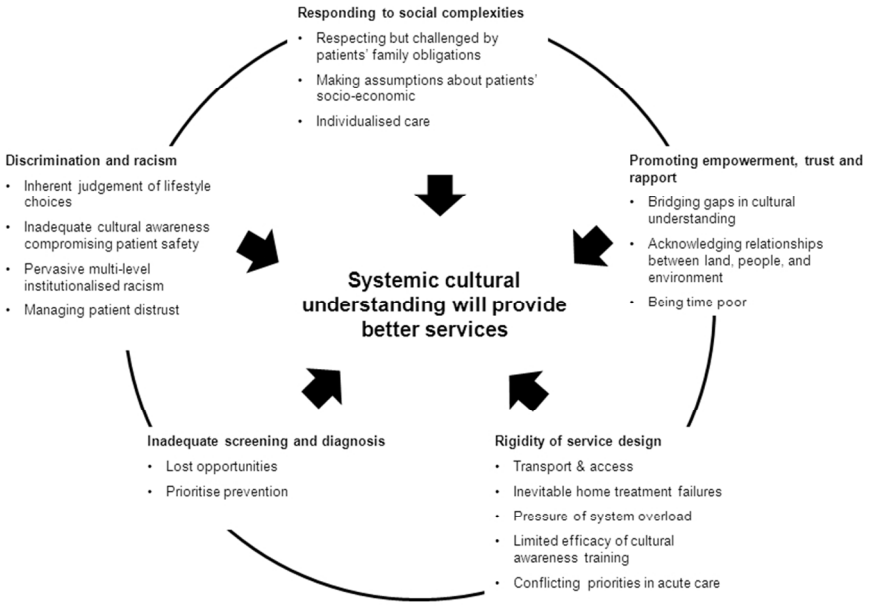

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Supplementary File. COREQ Checklist

No.	Item	Comment
Domain 1: Research team and reflexivity		
1	Interview/facilitator	ER
2	Credentials	ER (BN, Hons,), LB (PhD, AO), SW (PhD), JS (MPH, Dip ED.) AT (PhD, MPH, MM)
3	Occupation	ER (PhD candidate/Renal Nurse); LB (Head of School, Professor), SW (Sub-Dean, Early Career Researchers) JS (Ass. Professor, Indigenous Health) AT (Research Fellow)
4	Gender	ER, LB, JS, AT (Female)
5	Experience and training	ER has conducted qualitative research using a variety of methodologies, is a practicing renal nurse and PhD candidate with the University of Sydney
6	Relationship established	None
7	Participant knowledge of the interviewer	ER was known to some of the participants as a renal colleague and through professional interest in clinical and policy relevant issues in end-stage kidney disease.
8	Interviewer characteristics	ER is a social researcher and renal nurse with a focus in chronic disease and Indigenous health.
Study design		
9	Theoretical framework	Grounded theory
10	Sampling	Purposive
11	Method of approach	Face to face by
12	Sample size	Refer to Table 1
13	Non-participation	N=2 due to clinical commitments
14	Setting of data collection	Office or hospital meeting room
15	Presence of non-participants	None
16	Description of sample	Refer to Table 1
17	Interview guide	See Appendix
18	Repeat interviews	Single interview conducted
19	Audio/visual recording	Interviews were audio recorded
20	Field notes	ER recorded field notes
21	Duration	40 to 60 minutes
22	Data saturation	Yes
23	Transcripts returned	Yes
Analysis and findings		
24	Number of data coders	ER
25	Description of the coding tree	No
26	Derivation of themes	Inductively derived from data
27	Software	Nvivo
28	Participant checking	Yes
29	Quotations presented	Refer to Table 2
30	Data and findings consistent	Quotations provided to illustrate each theme.
31	Clarity of major themes	Yes
32	Clarity of minor themes	Yes

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Service providers' perspectives, attitudes and beliefs on health services delivery for Aboriginal people receiving haemodialysis in rural Australia: A qualitative study

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ABSTRACT

Objective

Providing services to rural dwelling minority cultural groups with serious chronic disease is challenging due to access to care and cultural differences. This study aimed to describe service providers' perspectives on health services delivery for Aboriginal people receiving haemodialysis for end-stage kidney disease in rural Australia.

Design: Semi-structured interviews, thematic analysis

Setting: A health district in rural New South Wales, Australia

Participants: Using purposive sampling, 29 renal and allied service providers were recruited including: nephrologists, renal nurses, community nurses, Aboriginal health workers, social workers and managers. Six were Aboriginal and 23 non-Aboriginal.

Results:

Improving cultural understanding within the healthcare system was central to five themes identified: rigidity of service design (outreach, inevitable home treatment failures, pressure of system overload, limited efficacy of cultural awareness training, conflicting priorities in acute care); responding to social complexities (respecting but challenged by family obligations, assumptions about socioeconomic status, individualised care); promoting empowerment, trust and rapport (bridging gaps in cultural understanding, acknowledging relationship between land, people and environment, being time poor); distress at late diagnosis (lost opportunities, prioritise prevention); and contending with discrimination and racism (inherent judgement of lifestyle choices, inadequate cultural awareness, pervasive multi-level institutionalised racism, managing patient distrust).

Conclusions

Service providers believe current services are not designed to address cultural needs and Aboriginality, and that caring for Aboriginal patients receiving haemodialysis should be

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family-focussed and culturally safer. An Aboriginal specific pre-dialysis pathway, building staff cultural awareness and enhancing cultural safety within hospitals are recommended. Increasing patient support for home haemodialysis may improve health and quality of care outcomes.

Keywords

Aboriginal, cultural safety, end-stage kidney disease, haemodialysis, rural

Article summary

Article focus:

- To elicit clinician perspectives, beliefs and attitudes about working with Aboriginal haemodialysis recipients in rural Australia
- To identify strategies to improve experience, safety and treatment outcomes

Key messages:

- Service providers believe there needs to be cultural understanding at the systemic level to enable provision of flexible and culturally safer treatment and care for rural Aboriginal haemodialysis patients
- Additional renal nurse support is needed to enable Aboriginal people to access home haemodialysis, keeping families and communities intact.
- Patient-centred care should be replaced by family-centred care for Aboriginal people with serious chronic disease to improve health and quality of care outcomes

Strengths and limitations of this study:

- We actively sought a broad range of views and experiences through purposive sampling.
- Our study included only service providers within a rural area of New South Wales, Australia

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INTRODUCTION

In Australia, the incidence of end-stage kidney disease (ESKD) is eight times that of non-Indigenous populations[1,2].Haemodialysis (HD) is the most common life sustaining treatment for Aboriginal patients with ESKD. Health disparities, reluctance to engage with health services, miscommunication, and poorer treatment outcomes have been reported in Aboriginal people receiving HD[3,4]. Similar disparities and challenges exist for Indigenous peoples of other first world nations, for example Canada, New Zealand and the United States[2,5].

Australian Aboriginal people suffer higher levels of mortality and morbidity from kidney disease than non-Aboriginal Australians[6]. Diabetes is a leading contributor to ESKD and is a co-morbidity in the majority of patients, with frequent poor management of blood pressure and glycemic control also contributing factors[7,8]. Socio-economic disadvantage and late referral to a nephrologist are also known to increase morbidity and decrease survival time for ESKD patients[9,10].

Providing health services to minority cultural groups with chronic disease is challenging because of access and negotiating cultural differences[11,12]. In the Aboriginal population, further complications arise from past traumatic experiences when accessing mainstream health services[13,14]. The history of colonisation and the resulting trauma experienced has perpetuated distrust of western healthcare organisations[15]. Power imbalances and lack of understanding between service providers and Aboriginal patients still exist 16].

Healthcare providers working with Aboriginal people have a responsibility to ensure cultural safety. Shortfalls in cultural safety limit Aboriginal patients' ability to access information

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about their disease and treatment[17]. This can contribute to reduced treatment adherence and increased morbidity and mortality for people already suffering a heavier burden of chronic disease compared to non-Aboriginal Australians[18,19]. Lack of trust and rapport between clinicians and Aboriginal patients can result in patient disempowerment and suspicion towards healthcare services[20]. The attitudes of healthcare providers shape how care is provided to patients and can influence health service design.

This study describes service providers' perspectives on health services delivery for Aboriginal HD recipients in a rural region of NSW, Australia. A better understanding of this can inform strategies to promote cultural safety and improve quality of care.

METHODS

Participant selection and setting

Participants were recruited in a rural/regional location using a purposive selection strategy[21] to increase diversity across health professionals from a range of disciplines, years of experience, age and gender. Participants were identified by consulting senior clinicians and Aboriginal health workers. There were 23 non-Aboriginal and 6 Aboriginal participants. Disciplines included in the sample were: medical, nursing (renal, community and nurse practitioner), renal case managers, hospital management, health policy, social work, Aboriginal health workers and Aboriginal liaison officers. Interviews were held at a time and place designated by participants. Ethical approval was obtained from the local health service and the University of Sydney. Written consent was obtained from all participants.

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Data collection

Semi-structured face-to-face interviews were conducted with service providers involved in the care of rural Aboriginal patients receiving HD. The question guide was developed informed by literature and discussion among the research team. To stimulate discussion, participants were asked to read three case studies that were adapted from interviews with Aboriginal clients of the services (Appendix A). These were developed in consultation with senior clinicians and piloted on several renal nurses, who gave positive feedback on how these 'real life' scenarios enabled them to focus on the challenges facing their Aboriginal patients. Based on interviews with 18 rural Aboriginal patients on HD these case studies encompassed the key concerns identified by patients. Participants were asked to read the case studies prior to being interviewed. This helped to ensure that the interviews covered issues that were important to patients. This strategy was useful in eliciting participants' levels of cultural knowledge, attitudes and beliefs, based on 'real life' scenarios in a non-confronting manner. This approach accords with grounded theory where 'the entire research process is interactive…we bring past interactions and current interests into our research, and we interact with our empirical materials and emerging ideas'[22].

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Interviews were conducted between July and November 2012. Each interview averaged one hour, facilitated by the lead author (E.R.). Interviews were digitally recorded and transcribed. ~~The interviews ceased when theoretical saturation was reached from concurrent analysis i.e. when no new concepts were arising.~~ Data analysis was conducted concurrently during data collection in accord with grounded theory methods[22]. Theoretical saturation[23] was reached at approximately 24 interviews, however with a total of 29 of 31 invitees responding and wanting to be participants, it was considered respectful and appropriate to interview all 29.

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Analysis

The first author led the analysis documenting preliminary concepts. Transcripts were entered into NVivo 10 (™ QSR International) for coding, searching and organisation of qualitative data. While not assuming to generate new theory with a relatively small circumscribed study in one location, the methods for this study were adapted from grounded theory. This was an appropriate methodology for beginning to develop relevant theory grounded in the participants' perspectives to inform health service delivery[21]. Concepts were documented inductively, grouping similar or overlapping themes, patterns, relationships and common or divergent perspectives[24]. This method followed Strauss's grounded theory 'coding paradigm', where theories are developed by interaction with the data. Coding moves from open (opening up the data to develop concepts) through to axial (the coding focuses around developing concepts) to selective coding (focussing on one category at a time). Explanations are discussed, reflected upon and built from dense coding[25].

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To enhance the analytical framework and ensure rigour, interpretation of the data and emergent themes were discussed with members of the research team. Member checking was conducted by returning transcripts to participants to check for accuracy and inviting participants to meet and discuss the preliminary analysis. Participants confirmed the analysis and themes reflected their perspectives, attitudes and beliefs about service provision to Aboriginal people receiving HD. Validity and accuracy of the data analysis was thus enhanced by seeking multiple perspectives (i.e. triangulation) including: patient perspectives gained from a reference group of Aboriginal renal patients and Elders who guided the study; confirmation by discussions with participants; and involving multiple researchers from

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different disciplines in the analysis[26]. The first author used self-reflexivity to check for potential biases from her dual clinician/researcher role, that may have influenced decision making throughout the study[26,27].

RESULTS

Participant characteristics are provided in Table 1. Of the 31 invited, 29 (93%) consented to participate in the study, two were unable to participate due to clinical commitments. We identified five themes: rigidity of service design, promoting empowerment, trust and rapport, responding to social complexities, distress at late diagnosis, and contending with discrimination and racism. Table 2 provides quotations illustrating themes, and a thematic schema is provided in Figure 1.

Rigidity of service design:

Participants felt frustrated and powerless to improve Aboriginal patient's experience of HD due to constraints of current service design and delivery. They believed service design was too rigid for the diverse needs of Aboriginal people. They expressed a desire for policy makers to implement new flexible strategies for this client group.

Transport and access ~~*Outreach*~~

Most participants were aware of major logistical challenges for rural Aboriginal people accessing HD. Many believed poor transport arrangements restricted access and patients' ability to attend dialysis and the other frequent appointments renal patients require. Participants described many instances of Aboriginal patients' negative outcomes resulting

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from poor access, for example: inability to attend podiatry appointments resulting in reduced or loss of mobility.

Inevitable home treatment failures

Although participants perceived home HD training to be done well and tailored to individual needs, they expressed concerns regarding lack of adequate home nursing support. They felt a single home visit after patients were sent home with their HD machine, with follow-up some months later was insufficient. Participants were concerned about the burden of care placed on patients' families. Some believed lack of home support was setting Aboriginal patients up to fail on home HD, perceiving reluctance by patients or families to ask for advice or help.

Pressure of system overload

Many believed renal services were increasingly over-stretched and under pressure, with insufficient resources to provide the support and culturally safe environments they felt were vital to Aboriginal patients. Some saw lack of time to spend with individuals as culturally disrespectful of Aboriginal patients. Some perceived that system overload limited their capacity to communicate with patients regarding their HD, or treatment problems.

Limited efficacy of cultural awareness training

Some participants who had attended ~~a~~ the one day cultural awareness training felt that it reinforced differences between Aboriginal and non-Aboriginal people in a negative way, providing insufficient education to counter stereotyping and commonly held assumptions. Others felt that regular, ongoing training could be more effective in addressing current shortfalls in non-Aboriginal staffs' cultural knowledge. Aboriginal cultural awareness training is deemed mandatory for healthcare professionals within this health service, however

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the majority of participants reported they had not been given the opportunity to attend the one day session. While this training was deemed 'mandatory' most participants believed there were inadequate resources for sufficient training places or to backfill clinical staff to attend.

Conflicting priorities in acute care

The combination of chair based HD with acutely ill patients in the same setting was felt to be inappropriate. Participants perceived this as confronting, particularly for Aboriginal people, many of whom have seen family members die from ESKD. Clinicians who had to juggle the demands of acute clinical care and providing cultural safety for Aboriginal patients felt conflicted and confronted. Several participants reported they were seen by Aboriginal patients to lack cultural respect in acute settings and felt powerless to address this.

Responding to social complexities

Participants identified differences in their clinical interactions with Aboriginal patients compared with non-Aboriginal patients, acknowledging a need to adapt their communication styles. They perceived the need to support Aboriginal patients and address different and poorly understood social and cultural complexity and family obligations, which they believed influenced treatment adherence and health outcomes.

Respecting but challenged by family obligations

Many participants understood that patients experienced conflicts between family and treatment obligations, prioritising funerals and travel to family or cultural events above treatment. There was awareness of Aboriginal patients' connectedness to family and country that identified 'who' and 'what' they are. While they respected patients' priorities, they were

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uncertain about how to resolve the conflict between necessary treatment and patients' family commitments. They felt unable to help patients within a system they felt did not acknowledge the priority of family.

Assumptions about socioeconomic status

Some participants believed the financial burden placed on individuals impacted on treatment adherence for those on limited incomes. Sharing resources with family was culturally appropriate for Aboriginal patients which limited money for travel or to support treatment. Others however felt that it easy to stereotype Aboriginal clients, and warned that people should not make assumptions about socioeconomic status based on Aboriginality.

Individualised care

Participants believed that it was important to listen to the needs and concerns of patients in order to provide individualised care. To many this meant treating all patients as individuals, understanding their unique challenges, but emphasising the need to use simple and culturally appropriate language. They felt this was important in improving perceived shortfalls in Aboriginal patients' understanding of the complexity of their treatment regimens.

Promoting empowerment, trust and rapport

Building trust and rapport was believed to be vital when working with Aboriginal patients. Participants were aware that being on HD creates long term relationships between patients and clinicians, and acknowledged that when these relationships were not based on trust, disempowerment of patients often resulted. Most non-Aboriginal service providers acknowledged the need to build relationships before trust and rapport can develop.

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Aboriginal practitioners however stressed the need for a more family-focussed approach. They also believed non-Aboriginal health staff should be educated about the consequences of colonisation for Aboriginal people, and understand the damaging results of patients' past negative experiences with health services.

Bridging gaps in cultural understanding

Participants felt that a designated renal specific Aboriginal liaison or case manager, introduced at diagnosis could provide a cultural bridge between the patients, renal staff and services. They believed the role could encourage patients to better engage with their treatment and health services, by improving two way cultural understanding.

Acknowledging relationship between land, people and environment

Most participants were aware of Aboriginal peoples' relationships to family, land and the physical environment of the places they occupy. Many desired care models that deliver a culturally safer renal service to Aboriginal people, ideally in their homes. Some suggested that simple improvements to the environment of hospital renal units, by reconfiguring the physical layout could provide more comfortable spaces for Aboriginal people.

Being time poor

Participants working in renal units had limited time for effective communication with Aboriginal patients. They felt they lacked the ability to address the adverse effects of past traumas experienced within health services and the capacity to build Aboriginal people's trust and faith in their interactions within renal units. Some however believed that Aboriginal patients understood that nurses had busy workloads and would not feel ignored by their 'busyness'.

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Inadequate screening and diagnosis

The majority of participants voiced their awareness of Aboriginal people frequently being diagnosed late in the progression of their disease. Aboriginal informants working with renal patients and several non-Aboriginal participants felt that this was due to Aboriginal people's inherent mistrust of mainstream health services. There were also comments about many Aboriginal people having had family members pass away or experience high levels of trauma, resulting in their avoidance of screening from fear of being diagnosed with kidney disease themselves.

Lost opportunities

Frustration was expressed at poor access to screening in primary health care settings, delaying diagnosis. Participants were distressed by lost opportunities for slowing disease progression due to late diagnosis. Some stated that inclusion of family at diagnosis was a critical component in keeping patients engaged with pre-dialysis strategies to slow disease progression. Participants felt that if family members understood the purpose of pre-dialysis pathways, this may motivate them to encourage patients to participate and potentially avoid dialysis altogether. Providers believed that had impaired renal function been diagnosed earlier, premature deaths may be avoided and that early detection of CKD could prevent ESKD.

Prioritise prevention

Strong concerns were voiced about the need to educate Aboriginal people regarding their risk factors for kidney disease. Aboriginal participants and some non-Aboriginal participants stressed the importance of using family and Elders to pass on knowledge to younger

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generations. Some believed education strategies needed to be tailored to life experience and maturity, as these appeared to be seminal to Aboriginal peoples' understanding of their kidney disease. Others perceived that some patients would not learn until they were ready to hear about their disease.

Contending with discrimination and racism

Some participants believed that individual racism was a problem, while others considered racism to be part of the Australian 'white' culture, defining it as historical suspicion of a person of another colour or cultural background. Most agreed racism was a barrier to effective communication and their ability to develop positive relationships with Aboriginal patients. A few participants mentioned that Aboriginal people could recognise "racist" body language which contributed to patients' distress and insecurities.

Inherent judgement of lifestyle choices

A minority of participants acknowledged that they sometimes made judgements about Aboriginal people's lifestyles, admitting ignorance of Aboriginal cultural values. They felt critical of Aboriginal people, who they perceived were unemployed and not helping themselves. Three of the 29 participants felt threatened by Aboriginal people and afraid of them in the clinical setting, fearing aggressive behaviour by patients when they did not understand or agree with treatment.

Inadequate cultural awareness compromising patient safety

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Participants perceived insufficient cultural awareness of staff within hospitals which translated into lack of cultural safety for Aboriginal patients. The majority viewed Aboriginal patients as victims of individualised and institutionalised racism.

Pervasive multi-level institutionalised racism

Participants believed a health system that does not address the needs of minority cultural groups exhibited institutionalised racism. Some were distressed at the lack of an Aboriginal specific pre-dialysis pathway resulting in people not completing the programme. They were concerned that once diagnosed, Aboriginal people do not engage with pre-dialysis services until their crisis admission to hospital and an emergency initiation to dialysis.

Managing patient distrust

Participants were aware of Aboriginal peoples' fear of hospitalisation. Several stated that given the history of discrimination against Aboriginal people, they are surprised that patients actually sought 'western' medical intervention. Some related patients' stories they had heard from the past when children were taken from Aboriginal parents by welfare agencies if they attempted to access health services, or experiences of segregation and racism in hospitals. They believed that these experiences were still vividly implanted in Aboriginal people's memories, and patients still associated healthcare provision with trauma and discrimination.

Interrelation of themes

The five themes link together under the overarching theme of 'Systemic cultural understanding will provide better services' (Figure 1.). Each theme relates to this major theme, with most participants acknowledging that there is a systemic lack of cultural safety impacting on service delivery and health outcomes for rural Aboriginal renal patients. A

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basic mistrust of mainstream services is a barrier to early screening and detection. When eventually detected, issues of transport and access to community renal nurses make it difficult to keep people at home once they commence HD. When patients are forced to travel to in-centre HD, inadequate cultural awareness of staff and perceptions of pervasive institutionalised racism compound to make hospital based treatment culturally unsafe for Aboriginal people.

~~*Whilst we encourage the system where people get home dialysis as much as possible instead of in-center, the system doesn't support Aboriginal clients to be managed in the home. There's issues about water quality, issues about care or support, about a range of factors which limit the uptake of home dialysis for Aboriginal people. So we put in people who, and I'm generalizing here, don't like to be inside for long periods of time into an environment that's very rigid, very procedurally based, and we sit them down in a chair for three to five hours. Um, that isn't culturally sensitive for any culture let alone any Aboriginal culture*~~

~~(Senior health services manager)~~

DISCUSSION

Service providers caring for Aboriginal HD patients emphasised the importance of cultural safety and respect in promoting trust, rapport and patient empowerment. This involves cultural understanding and acknowledging the importance of patients' relationship to family and country. They recognised challenges such as racism, stereotyping, social complexities

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within Aboriginal families, inadequate cultural awareness training and conflicting priorities of providers, patients and health services delivery modes. Service providers urged for more advocacy and flexibility for Aboriginal patients receiving HD.

Studies in remote and metropolitan settings have found that lack of cultural safety and access issues have major implications for the well-being of Aboriginal renal patients[4,28-30]. This paper reports similar challenges for rural dwelling renal patients, recommending strategies to address these. A 2010 study in remote Australia demonstrated that provision of culturally appropriate services, provided by an Aboriginal controlled medical service has resulted in Aboriginal HD outcomes being comparable with those of non-Aboriginal Australians[31].

Other studies have found culturally inappropriate healthcare, exposure to racism and poor communication[14,32,33] to be among barriers to care for Aboriginal people with chronic disease. This study however has identified that providing family-focussed care, improving cultural awareness training and Aboriginal specific care pathways and delivery could improve treatment, but also address Aboriginal people's historical distrust of mainstream health systems.

According to Taylor and Guerin, 'cultural safety is achieved when the recipients of care deem care to be meeting their cultural needs'[34]. Cultural safety involves examining institutional structures, acknowledging assumptions, addressing power imbalances between clinician and patients, and respecting Aboriginal cultural norms. Recent local work suggests that the current model of cultural awareness training for Australian health professionals requires improvement[17,35]. Cultural awareness training for healthcare providers should involve

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ongoing education about the priorities, values and preferences of Aboriginal patients as well as practical strategies to build trust and rapport within clinical settings.

Major barriers to access in rural areas included lack of transport to attend dialysis and frequent, multiple appointments associated with their treatment. Providing home HD was recommended by healthcare providers, but is currently limited by inadequate nursing staff[36]. Home HD for remote Aboriginal patients is known to increase compliance and self-care when patients are given responsibility for their treatment, resulting in better quality of life and outcomes[37,38]. Additional in-home renal nurse support is suggested for sustaining home HD for Aboriginal patients and requires reassignment of resources and priorities. Avoidable acute care episodes and late diagnosis and management suggests urgent economic studies are needed to inform the costs of providing flexible, Aboriginal-focused care.

Successful treatment of chronic disease for Aboriginal people requires community consultation, local knowledge and collaboration between mainstream services and Aboriginal controlled health services[32]. The vital role of family in Aboriginal culture was acknowledged by participants. Although they felt challenged by the social complexities relating to family, most agreed that Aboriginal peoples' connectedness to country and family is crucial to health and well-being. These connections are well known within Indigenous societies, where family obligations are frequently prioritized above the individual[39,40].

A family-centred philosophy for Indigenous people with chronic disease, rather than an individual-based patient-centred philosophy is recommended to address the relational nature of most Indigenous societies. The translation of knowledge down the generations by

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Aboriginal people, with the role of family and Elders in passing on important information about chronic disease is crucial [33]. Participants acknowledged the impact of previous trauma experienced by Aboriginal people when encountering health services. Family-centred care may play an important role in addressing this by empowering patients and families to communicate with service providers about achieving culturally appropriate care.

Institutionalised racism was identified by healthcare providers in our study and is known to contribute to persistent health disparities in countries where Indigenous people have been colonised[41]. There is a need to provide treatment and care that addresses different belief systems[11,12]. Participants cited the lack of a separate Aboriginal engaged and led pre-dialysis pathway as an example of pervasive institutionalised racism. Devising a culturally appropriate pre-dialysis pathway, in conjunction with a renal specific Aboriginal advocate/support person, could provide a cultural bridge. This simple and affordable strategy may assist in reducing late diagnosis and crisis commencement onto HD, which is common for Aboriginal people [39] and known to increase morbidity and mortality [9]. This support role may also provide education and support for those caring for a family member facing ESKD and HD[4].

Healthcare providers believed that universal screening for CKD in Aboriginal people can slow disease progression and potentially avoid the need for HD[42]. Further, involving Elders and family in prevention strategies was deemed important, requiring more collaboration between renal services and Aboriginal controlled medical services, a trusted source for screening in Aboriginal communities.

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Our study includes a range of healthcare providers involved in the care of Aboriginal HD recipients, making explicit many of the challenges and barriers in providing culturally safe and respectful care. However, there are some limitations. Data was collected from one rural locality therefore transferability to other areas may be limited. We would however argue that our use of purposive sampling gave considerable strength to this study by including a diverse and broad range of perspectives and experience, therefore increasing the potential for transferability of findings and recommendations for service delivery to Aboriginal people experiencing renal disease in other rural communities[43]. This study has focussed on services for Aboriginal people on HD only and not included peritoneal dialysis (PD) because there were no Aboriginal patients receiving PD in the rural region at the time of this study. Further research exploring service delivery for Aboriginal people receiving PD is recommended.

Conclusion

Service providers believe current services are not designed to address cultural needs and Aboriginality, and that caring for Aboriginal patients receiving haemodialysis should be family-focussed and culturally safer. Prioritising prevention by increased screening and education about kidney disease is paramount. An Aboriginal specific pre-dialysis pathway, building staff cultural awareness and enhancing cultural safety within hospitals are recommended. Increasing patient support for home haemodialysis may improve health and quality of care outcomes. Implementing the recommendations from this study may also help in addressing patient mistrust of mainstream health services and reduce the impact of institutionalised racism on Aboriginal renal patients

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~~Service providers believe that cultural safety is fundamental in caring for Aboriginal people in rural renal services. This requires a better understanding among healthcare providers of the values and priorities of Aboriginal patients and building trust and rapport within mainstream services. Family-centred care, including better support for home haemodialysis, an Aboriginal specific pre-dialysis pathway and Aboriginal led community screening are likely to improve health and quality of care outcomes.~~

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Table 1. Participant characteristics

Characteristics	Interviewees (n)	(%)
Gender		
Male	11	(38)
Female	18	(62)
Aboriginal	6	(21)
Non-Aboriginal	23	(79)
Years of experience working with Aboriginal renal patients		
<5	2	(7)
6-10	9	(31)
11-20	11	(38)
>20	7	(24)
Role		
Senior Management/Policy	3	(10)
Nephrologist/VMOs	3	(10)
Hospital medical officer	1	(3)
Nurse Unit Manager	4	(14)
In-centre renal nurse	4	(14)
Home dialysis nurse	2	(7)
Community nurse/Nurse practitioner	4	(14)
Social worker	2	(7)
Aboriginal Health Worker	4	(14)
Aboriginal Liaison Officers	2	(7)

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Table 2. Participant quotes table

Theme	Illustrative quotations
Rigidity of service design	
Outreach	Obviously transport's a huge issue and not necessarily something we can have an effect on. Its difficult because most clients don't actually live here in town yet this is the only centre that's available. (Female, 40s)
	One of the big things in particular is transport. . . In Queensland they use a bus… it travels all around and picks up everyone. (Male 30s)
	I would be aware that transport's probably the biggest issue for Aboriginal people accessing renal dialysis here' (Aboriginal male, 40s)
Inevitable home treatment failures	We need someone basically full time to be able to do home visits, home assessments, … but a lot of the time its hard, so if you've got people out in remote communities or towns. I mean it's so time consuming. (Male, 30s)
	I think that people going on home haemodialysis need extra support, and I can absolutely feel for the home haemo staff because you're cutting an umbilical cord and then you just sit and wait because you know they're gonna come back no matter who they are. (Female, 30s)
	It's culturally appropriate to stay at home but it's not culturally appropriate to put all that expectation on that person and on their family members … like a punitive approach when it's not maintained, to the point of being so unwell, being in hospital and it being a failure. (Female, 30s)
Pressure of system overload	The whole system is so busy and creaking all the time, . . . people lacking time to spend with them is often mistaken for cultural disrespect . . .we don't listen to people. We don't often identify what their needs are and we don't spend time identifying problems, sorting them through, explaining things to individuals.(Male, 50s)
	It's rush-rush-rush," let's get them on let's get them off". Um it doesn't matter which way you package that's what dialysis units are in an acute setting. ' (Female, 40s)
Limited efficacy of cultural awareness training	I don't believe you can do that as a one off because that's just a drop in the ocean, that's like saying "tick I've done that" and that's useless. There's got to be some sort of ongoing mechanism ongoing culture within the organization that supports that ethos constantly (Female, 30s)
	It's interesting I watched the reactions of the people in the group I was with and I think the people that left that day with no real joy are probably feeling more polarized and could identify the start of the day with that feeling as well. (Female 50s)
Conflicting priorities in acute care	It's hard that balance. When you're busy and clinical, and I've always found if you spent more time with the patients you get into getting an understanding of their stuff and you can usually work out a fairly acceptable relationship with the client. But there is often no time (Female 50s)
	Often the lack time that people have to spend with them is mistaken for lack of cultural disrespect and I think that the reality of it is the fact that we don't listen to people we don't often identify what their needs are and we don't spend time identifying problems, sorting them through, explaining things to individuals. (Male, 50s)
Responding to social complexities	
	'OK Societal disadvantage, you know that they are starting from a more difficult place than the majority of other white or you know non-Aboriginal renal patients. When you hear that someone is Aboriginal you know that there's a really good chance that they're going to more complicated from a social point of view, that they're going to need more support and will need more assistance in walking the walk through the whole gamut that comes with having to conform to a way of being that's going to be completely foreign to how they've been used to living their lives' (Female, 40s)
Respecting but challenged by patients' family obligations	They put funerals and family in front of their dialysis. It's like their health comes second and I understand that because that's part of their culture but I see the consequences of it. (Female, 40s)
	So they could actually do two days in a row and then miss a couple and if there was

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Theme	Illustrative quotations
	more flexibility in the days ….we find if there is any funeral or family obligations, they will miss their dialysis in preference to that (Female, 40s)
	That's one of the biggest roots of the difficulties for Aboriginal people with dialysis is that in their reality there is no true sense of self, but it' all about community. But our health system is dependent on self-confidentiality, privacy, um reliant on health literacy. Whereas the Indigenous culture is about community ownership (Female, 30s)
Making assumptions about patients' socioeconomic status	I think it's very easy to assume they all are going to be socio or economically and transport disadvantaged and that is not actually always true and it is a trap to fall into that assumption . . . every case will be different.' (Female, 50s)
	If they're a low social economic group whether they be Aboriginal or non-Aboriginal there's that element of similarity because of the financial and lack of education. But it comes back to the difference is there's probably more support and encouragement for a non-Aboriginal person to participate in those renal dialysis units.' (Aboriginal Male 40s)
Individualised care	Everyone is totally individual. I assess on that basis as time goes on for each patient, regardless of who they are. (Male, 30s)
	So, I think with supporting and just understanding and caring and being patient with the patients, because everyone's an individual and everyone's got different issues or feeling different about things at different stages' (Aboriginal female, 40s)
	'I actually think those challenges as for non-Aboriginal people will be very much related to their individual backgrounds' (Female, 50s)
Promoting empowerment, trust and rapport	
Bridge gaps in cultural understanding	I would like to see more Aboriginal staff there . Even if it's apart from the hospital liaison person. But just someone there who they can relate to, who they can sit down and talk to, and who can relay their messages across to the non-Aboriginal staff. (Aboriginal female, 60s)
	They're a nice medium between the health service and their community …supporting vulnerable people and directing them, just basically giving them someone to go alongside the journey with them' (Female, 30s)
Acknowledging relationship between land, people and environment	For me it is understanding the intricate respect of land, of people, of the environment and all those things that makes us whole as an Aboriginal person that makes an Aboriginal person who they are. (Aboriginal male, 40s)
	You need big windows, no one facing each other so in that whole the physical setup and environment of those units are much more culturally aware or in tune. (Female, 50s)
Trust and rapport	I think there's is a bit an element of lack of understanding of the past policies that were in place where Aboriginal people were taken away from hospitals removed, the stolen generation and the grief and loss that associates with that.(Aboriginal male 40s)
	I guess that's where service providers need to understand that they need to build the relationship and the trust .They need to spend time with them and not just treat them as like a number. (Male, 40s)
Being time poor	'I doubt that it is that simple as the nurse is too busy to talk to, because I have had many Aboriginal patients say to me "my God you've had a busy shift you been flat out, you haven't had time to stop". They've got insight into that.' (Female, 50s)
	They feel that they're not listened to or that they don't get the time that they need because it's always such a rush to get everyone on (Female 40s)
Inadequate screening and diagnosis	
Lost opportunities	So we've got Aboriginal people dying of renal disease who don't even know and their GP's have not even made the diagnosis. And it may be that they're not going to GP'. (Female 50s)
	it has to go back to primary health care, I think. You've got to diagnose and prevent. (Female 40s)'
Prioritise prevention	I mean there's more younger people getting kidney disease that I know of out in the communities but they're not doing anything about it. (Aboriginal female staff member, 60s)
	CKD screening was ruled out by the Department of Health two years ago. Not one

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Theme	Illustrative quotations
	health district been able to implement it in New South Wales because there are no resources allocated for it . . .So nobody's been able to implement it' (Female, 50s)
Contending with discrimination and racism	
	I think they do see discrimination. . .I think it comes from something that isn't just a system error. I think it is a community problem.' (Female 50s).
Inherent judgement of lifestyle choices	Sometimes I feel real empathy and compassion and understanding and some days it's just like "Get over it, go and get a job you lazy little ass". I've had to work, no one gives us a free ride. (Female, 40s)
Inadequate cultural awareness compromising patient safety	From a cultural awareness perspective I think we could all do with more cultural awareness in our workplaces' (Female, 30s))
Pervasive multi-level institutionalised racism	Once they are on that machine the system has failed and the system will have had many opportunities for interventions. So the challenge is actually to get effective reasonable pre- dialysis, pre-end stage care. (Female, 50s).
Managing patient distrust	They come with pre-perceived ideas. If people have had a bad experience in the past then that's it for everyone. (Female,40s)

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Conflict of interest

No conflict of interest has been declared by the authors

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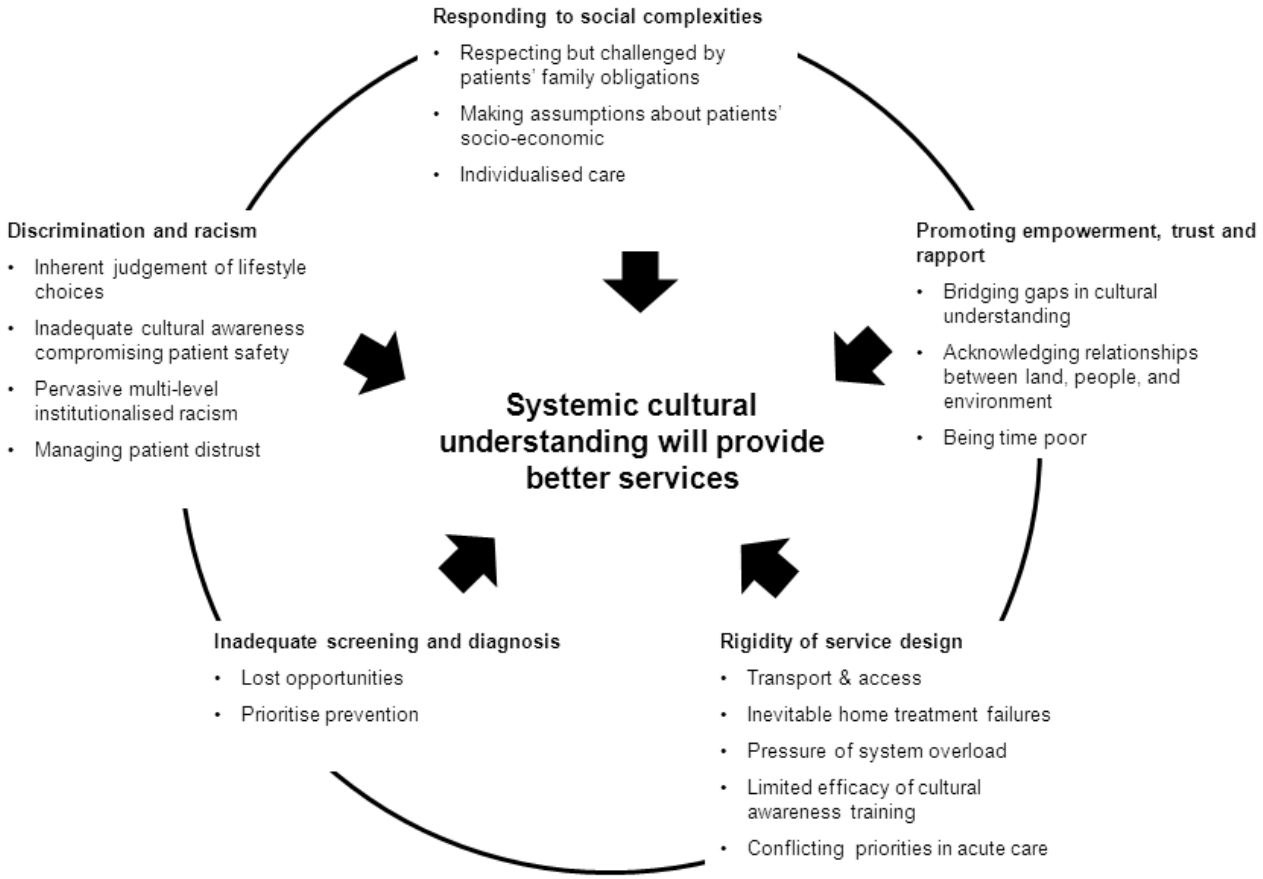
Figure 1. Thematic Schema



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Appendix A.

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Case Study one

An Aboriginal man on haemodialysis in his mid 30s lives in a remote location with his family. He had tried living in town but found the Housing Department house he was allocated was in an area where there was significant conflict and the issues of the other residents impacted negatively on his family. He moved home to his community to be with his family support network. He has to travel 170 kms return to access his dialysis. Even though he cannulates himself and is self-caring within a renal unit, his wife is not confident to support him at home with dialysis. His children are too young to take on this responsibility. This man fears he is too far from help to have home dialysis and has reported that the ambulance takes too long to get to his community were he to have a problem. He is now faced with having to move back to town as the travel has become unaffordable and unsustainable.

Case study 2

A 54 year old Aboriginal woman is on haemodialysis and has significant problems with vascular surgery and access. Surgery leaves her with permanent nerve damage to one leg, resulting in high levels of pain requiring analgesia. She now has permanent loss of mobility and independence and has lost her driver's licence. This loss of independence is devastating for her and she is reliant on young family members and high doses of analgesia to function. There are significant transport issues for accessing dialysis at an in-centre renal unit. She reports ongoing problems at this unit with staff having what she considers limited cultural awareness. She says that "staff only tell me what to do" and feels they do not provide education or discuss her treatment with her. She also feels that staff avoid engaging with her and sees them spending time with other patients whilst not having conversations with her.

Case Study 3

A 60 year old Aboriginal man is having haemodialysis at home, after travelling three hours a day for three years to do in-centre dialysis. His niece is his carer, having been trained at the home training unit with him. This man however prioritises family commitments such as funerals and supporting others in need before his dialysis, resulting in irregular treatments. Despite this, he won't allow his niece to remove sufficient fluid during dialysis, and is regularly fluid overloaded. This triggers a series of acute hospital admissions and the patient finds himself once again forced to travel to have his weight stabilised. This becomes a pattern, with his niece unable to provide sufficient dialysis time and fluid removal to keep him out of hospital and in-centre dialysis.

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