
The perspectives of Aboriginal patients and their health care providers on improving the quality of hemodialysis services: A qualitative study

Elizabeth F. RIX,¹ Lesley BARCLAY,¹ Janelle STIRLING,¹ Allison TONG,²
Shawn WILSON¹

¹University Centre for Rural Health, The University of Sydney, Lismore, New South Wales, Australia;

²Sydney School of Public Health, The University of Sydney, Sydney, New South Wales, Australia

Abstract

Chronic kidney disease has a higher prevalence in Indigenous populations globally. The incidence of end-stage kidney disease in Australian Aboriginal people is eight times higher than non-Aboriginal Australians. Providing services to rural and remote Aboriginal people with chronic disease is challenging because of access and cultural differences. This study aims to describe and analyze the perspectives of Aboriginal patients' and health care providers' experience of renal services, to inform service improvement for rural Aboriginal hemodialysis patients. We conducted a thematic analysis of interviews with Aboriginal patients (n = 18) receiving hemodialysis in rural Australia and health care providers involved in their care (n = 29). An overarching theme of avoiding the "costly" crisis encompassed four subthemes: (1) *Engaging patients earlier* (prevent late diagnosis, slow disease progression); (2) *flexible family-focused care* (early engagement of family, flexibility to facilitate family and cultural obligations); (3) *managing fear of mainstream services* (originating in family dialysis experiences and previous racism when engaging with government organizations); (4) *service provision shaped by culture* (increased home dialysis, Aboriginal support and Aboriginal-led cultural education). Patients and health care providers believe service redesign is required to meet the needs of Aboriginal hemodialysis patients. Participants identified early screening and improving the relationship of Aboriginal people with health systems would reduce crisis entry to hemodialysis. These strategies alongside improving the cultural competence of staff would reduce patients' fear of mainstream services, decrease the current emotional and family costs of care, and increase efficiency of health expenditure on a challenging and increasingly unsustainable treatment system.

Key words: Cultural competence, cultural awareness training, early screening, home hemodialysis

Correspondence to: E. F. Rix, BN (Hons)RN, PhD candidate, University Centre for Rural Health, The University of Sydney, PO Box 3074, Lismore, NSW 2480, Australia. E-mail: Elizabeth.rix@ncahs.health.nsw.gov.au
Funding: E. R. was supported by The Clinical Excellence Commission, Ian O'Rourke Scholarship in Patient Safety.

INTRODUCTION

Indigenous people globally suffer a significantly higher incidence of chronic kidney disease (CKD) leading to end-stage kidney disease (ESKD).¹ Australian Aboriginal people suffer eight times the incidence of kidney failure requiring renal replacement therapy than non-Aboriginal

© 2014 The Authors. Hemodialysis International published by Wiley Periodicals, Inc. on behalf of International Society for Hemodialysis.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

DOI:10.1111/hdi.12201

Australians.² Mainstream health institutions are challenged by providing accessible, acceptable, and efficient health services to Aboriginal people with serious chronic disease.³ A lack of cultural safety within health services can result in patients avoiding contact,⁴ leaving Aboriginal people at risk of late diagnosis of CKD, known to increase morbidity and mortality.⁵

Discrimination toward Aboriginal people when accessing health care is recognized as a social determinant of health.^{6,7} Racism is known to cause distrust and avoidance of hospital-based services^{8,9} by Aboriginal people. This contributes to their avoidance of screening and not presenting for treatment, from fear of being hospitalized.¹⁰ Institutionalized racism, embedded in organizations and how they operate causes a “clash of cultures” between Aboriginal people and non-Aboriginal institutions, which has a damaging impact on health and well-being.⁸

Patients from all cultural backgrounds can struggle with adherence to hemodialysis (HD) regimens, with access and family support among barriers and enablers to treatment adherence.¹¹ Research incorporating the perspectives of patients and their health care providers can inform service improvement and guide culturally appropriate and accessible care for minority cultural groups.^{12–14} The goal of this study was to inform service improvement based on the insights of consumers and those delivering their treatment and services.

METHODS

We conducted an investigation that consisted of three qualitative substudies. Interviews were conducted with rural Aboriginal patients receiving HD (n = 18) and their health care providers (n = 29). Both patient and health care provider data sets have been analyzed independently and are reported elsewhere¹⁵ (Rix, EF, Barclay, I, Stirling, J, Tong A, Wilson, S, “Beats the alternative but it messes up your life”: Aboriginal people’s experience of haemodialysis in rural Australia, 2013, unpublished data). These studies investigated the perspectives and experiences of HD services provided for rural Aboriginal HD patients. A third thematic analysis of the complete data set reported here answered the research question: How can Aboriginal HD patients’ and their service providers’ experience and perspectives inform improvement to renal services for Aboriginal people in rural Australia? A community reference group of patients, elders, and Aboriginal health workers guided the study. Ethical approval was obtained from the Local Health District, The University of Sydney and The Aboriginal Health and Medical Research Council of NSW.

Table 1 Aboriginal patient characteristics (n = 18)

Characteristic	N	%
Gender		
Male	9	(50)
Female	9	(50)
Age (years)		
30–39	4	(22)
40–49	2	(11)
50–59	8	(44)
60–69	3	(17)
70–79	1	(6)
Time on hemodialysis		
<1 year	2	(12)
1–5 years	3	(16)
5–10 years	10	(56)
>10 years	3	(16)

Setting

The study took place in a rural region of New South Wales, Australia. The region has one tertiary center renal unit, two satellite renal units, and home HD training facilities. Patients were aged 35 to 78 years, nine were men. Length of treatment ranged from 1 month to 14 years. Six resided in rural areas, seven in small towns and five in regional centers (Table 1.). Health care providers included nephrologists, senior managers, nurse-unit managers, in-center renal nurses, home training renal nurses, community nurses, renal nurse practitioner, renal social workers, Aboriginal health workers, and Aboriginal liaison/support roles (Table 2).

Data collection

Patients

Face-to-face in-depth interviews were conducted with 18 (86%) of the 21 Aboriginal people receiving HD treatment for ESKD within the participating renal service. Aboriginal participants were recruited using a “snowballing” technique.¹⁶ Interviews were conducted in the participant’s homes or another preferred venue, between March and October 2011. A “yarning” approach was used as a culturally appropriate method for the interviews.¹⁷ Yarning is a word used by many Aboriginal people, meaning “let’s have a chat.”¹⁷ The “yarning” interview technique involves an informal and reciprocal exchange of information consistent with Aboriginal communication styles. This approach is culturally appropriate, enhances participant rapport and promotes open and honest discussion.¹⁸ The unstructured nature of yarning provides participants

Table 2 Health care provider characteristics (n = 29)

Characteristic	N	(%)
Gender		
Male	11	(38)
Female	18	(62)
Aboriginality		
Aboriginal	6	(21)
Non-Aboriginal	23	(79)
Years working with rural Aboriginal patients		
<5	2	(7)
6–10	9	(31)
11–15	11	(38)
>15	7	(24)
Role		
Senior management/policy	3	(10)
Nephrologist/VMOs	3	(10)
Hospital medical officer	1	(3)
Nurse unit manager	4	(14)
In-center renal nurse	4	(14)
Home dialysis nurse	2	(7)
Community nurse/practitioner	4	(14)
Social worker	2	(7)
Aboriginal health worker	4	(14)
Aboriginal liaison officers	2	(7)

VMO = Visiting Medical Officer.

freedom to contribute in ways they feel comfortable. While there was no set interview guide, participants were encouraged with consistent prompts to “yarn” about their experience of engaging with their health care providers, and to suggest ways for improving their experience HD.

Health care providers

Semistructured interviews were performed with a purposive sample of renal and allied health care providers (see Table 2). Twenty-nine (94%) of 31 invited service providers consented to participate. Two were unable to participate because of competing work priorities. Interviews took place between July and November 2012.¹⁹ Three one-paragraph case studies, based on the actual patient interviews were read at the outset of the health care provider interview to enable the dialogue to focus on the issues and topics of importance to their patients. This strategy proved to be an effective tool in eliciting participants’ levels of cultural knowledge and their attitudes to working with Aboriginal people. A set of semistructured interview questions also guided these interviews. See Supporting Information Appendix S1 for case studies and interview questions/prompts. All interviews were conducted by the lead author (E. R.), and were recorded and transcribed verbatim.

Analysis

The lead author (E. R.) performed the initial data analysis. All participant transcripts were entered into a single version of NVivo 9™ (QSR International, Burlington, MA 01803 USA), to assist with coding and organization of data. Based on principles of grounded theory,²⁰ the lead author (E. R.) inductively coded concepts related to service provision, identifying convergence and divergence of concepts between the two participant groups. Extensive cross-checking of transcribed data was performed and discussed among the research team to clarify results. Further discussions with participants from both groups confirmed that themes generated in the combined and specific subgroup analyses were consistent with their experience and perception of current services.

Participants believed that the analysis of the combined data set that explored service delivery maintained the integrity of their own viewpoint, while providing an explanation that transcended their own contribution. The community reference group guiding the study and coauthors further scrutinized and critiqued the results, agreeing that of the inductive coding explained how services could be improved. We identified and labeled four themes arising from the data using language that was deliberately “descriptive” of the perspectives of the two groups. The themes therefore reflected participant congruence on service delivery and how this could be designed to reduce barriers to access and achieve Aboriginal social and cultural priorities (Figure 1). This figure demonstrates the separate and joint analysis of the data sets, providing visual confirmation of the overlapping concepts. The bottom half of this diagram links the congruent themes within the context of improving services for Aboriginal renal patients.

RESULTS

Both patients and health care providers emphasized the vital role of family and the importance of improving service providers’ understanding of the role family plays in treatment for Aboriginal HD patients. While the language they used differed, the meaning was similar (Table 3). All participants regarded building strong relationships between patients and health care providers as essential. Improving cultural safety, increasing understanding of clinicians, and the need for flexibly designed and family-focused services emerged, and was agreed by both groups. All participants were also concerned about the high incidence of late diagnosis and unplanned, emergency commencement of HD.



Figure 1 Synthesis of themes from rural Aboriginal hemodialysis patients and their health care providers.

Under an overarching theme of “Avoiding the ‘costly’ crisis,” we identified four pragmatic themes that relate to the goal of service improvement. The first was *engaging patients earlier*. Early detection was perceived as vital to prevent late diagnosis, slow disease progression and had potential to avoid dialysis altogether. *Flexible family-focused care* incorporated better engagement at diagnosis between services and family, and more flexibility within services to encompass family and cultural obligations. The third theme, *managing patient fear of mainstream services* described fear driven by experiences of family members on dialysis, and a history of racist treatment received by Aboriginal people when engaging with government organizations. It also included increased support for home HD and renal-specific Aboriginal support to counter avoidance of hospitals. The final theme was *service provision shaped by culture*. This included improving current cultural awareness training, which was ineffective. Partici-

pants believed that elders delivering cultural education may increase two-way understanding between patients and clinicians. Additional examples of data that informed this analysis are provided in Table 3.

Engaging patients earlier

Patients reported late diagnosis and emergency commencement of HD. Health care providers believed that earlier detection of CKD in Aboriginal people would slow disease progression and could potentially minimize the need for HD; however, both groups expressed concerns at Aboriginal people’s reluctance to be screened, exacerbated by inadequate engagement with mainstream services.

All participants acknowledged the need for universal screening for CKD for Aboriginal people. Both groups reported their awareness of the high incidence of renal

Table 3 Additional illustrative quotations supporting each theme

Quotations: Patient	Quotations: Service provider
Engaging patients earlier	
<p>“I didn’t know I had kidney problems cause I was pretty active, fishin’ huntin’ golfin’ . . . until one day I felt a bit crook there . . . so they rushed me to hospital and when I woke up I was in the intensive care ward . . . and they said “Oh you have to go down to dialysis and get blood into you, your kidneys have had it.” (Aboriginal man, 50s)</p>	<p>“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 . . . in their 40s or 50s with hypertension, cardiovascular disease, but they will have an underlying renal failure.” (Senior Manager)</p>
<p>“Yeah you think I’d have woke up a bit you know what with my father being on it, and passing away on it, but I just thought it’s never happen to me, as a lot of young fellas do. I was only 34 when I started.” (Aboriginal man, 30s)</p>	<p>“Unfortunately most Aboriginal patients didn’t come through the pathway they usually crashed and burned. . . . and you know they wouldn’t attend appointments with the nephrologist and things cause it’s just like, ‘no this is not happening’, so that’s denial. In saying that though it has to be earlier, it has to be at the AMS.” (Dialysis nurse, 40s)</p>
Flexible family-focused care	
<p>“When this all happened I got them all together to have a family conference concerning my health and then my oldest boy put his hand up and said ‘Mum I’ll give you my kidney’, my other son jumped and said ‘well Mum I’ll come and be your carer’. And my baby son put his hand up and he said ‘Mum I’ll learn the machine with you’, so straight away the family was on to it , wanted to deal with it with me.” (Aboriginal woman, 50s)</p>	<p>“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.” (Dialysis nurse, 40s)</p>
<p>“You cannot expect a lot of Aboriginal people to take on the dialysis responsibilities in their own homes we need more support . . . People have gotten used to being institutionalized. But if they had some encouragement they could do it . . . Because what we’re doing the wrong is taking our people out of country and breaking their cultural spirit, and this is wrong.” (Aboriginal woman, 50s)</p>	<p>“I think the hardest thing is working in the health care system and working with Aboriginal people is their problems. I find it difficult when you’ve got scenarios where he puts all his family first and arrangements for a funeral and all that. That’s very common, you know, they’ve definitely got lots more commitments other than dialysis and dialysis isn’t a priority for them at those times. That’s difficult when you try and run a unit.” (Dialysis nurse, 20s)</p>
Managing patient fear of mainstream services	
<p>“I think they need to get back to school . . . learn about Aboriginal issues and have cultural values about ‘em, Aboriginal cultural values. Because half the time their attitude towards Aboriginal issues and values keeps Aboriginals away. Sometimes Aboriginals don’t want to go and listen to ‘em, they stay away and at the end of the day the Aboriginal suffers.” (Aboriginal man, 40s)</p>	<p>“They come with pre-perceived ideas. If people have had a bad experience in the past then that’s it for everyone.” (Nurse, 40s)</p>
<p>“Its not because of our Mum’s neglect, its because of the times, the type of life, where at the time Aboriginal people just couldn’t take their children to the doctor, otherwise they’d be classed as unfit, yeah, even my Grandmother feared for my safety cause there was an uncle that used to be a taxi driver and he used to always come down and check to see if I was OK and I was still there.” (Aboriginal woman, 50s)</p>	<p>“They’ve probably got good reason to feel a little bit that way (<i>Discriminated against</i>) at times because, I mean in general they’ve come from the history of Aboriginals where they’ve felt isolated. They’re still dealing with it, they’re still ya know talking about it. . . . Oh I don’t feel like the renal staff do it intentionally at all, but that separation is there and we need to acknowledge it a little more maybe.” (Renal nurse 30s)</p>
	<p>“They’ve had other family members who have been through the same process prior to them, so they’re already hyped up to be scared of what’s going on, their family members may have died.” (Home dialysis nurse)</p>

Table 3 Continued

Quotations: Patient	Quotations: Service provider
<p>“See over there (<i>in acute unit</i>) on that machine you can’t talk to em, they go from person to another person and then the alarms go off you know, well you can’t ‘ave a good conversation with em while you’re there.” (Aboriginal woman, 60s)</p> <p>“When they did take me down to the renal unit to have a look at the machines and how things were going to happen, I just saw the blood and took off. It was the same as when the doctor first told me that my kidneys were failing I ran out of the surgery, and it’s very sad really, it makes me sad now because I was very naive about dialysis and kidneys.” (Aboriginal woman, 60s)</p>	<p style="text-align: center;">Service provision shaped by culture</p> <p>“I think, let’s be real, here I think whether we like it or not there’s still a bit of racism out there. I mean polite but you know it’s out there and it’s sad. Mainstream, when I used to give talks to nurses and doctors coming through the system, I’d always say to them . . . ‘you just provide a little bit of TLC to an Aboriginal patient and our people, they’re good at reading body language, and they can pick up if you’re genuine or not’. Ultimately if you showed a bit of TLC you’ll have a friend there for life, you know, a friend for life.” (Manager, Aboriginal Medical Service)</p> <p>“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 like a number.” (Health services manager, 40s)</p>

disease in Aboriginal populations, but were frustrated by a lack of resources to implement this in rural regions. For example:

A lot of Aboriginal people they neglect themselves in many areas and until the last minute . . . it could of been prevented but you know you need to resources and staff to come out and set programmes up. (Aboriginal man, 60s)

Once they are on that machine the system has failed and the system will have had many opportunities for interventions. So the challenge for Aboriginal people is actually to get effective reasonable pre-dialysis, pre-end stage care that is the single biggest challenge these people face. (senior manager)

Participants from both groups believed that involving elders and family in prevention strategies was vital. Collaboration between renal services and Aboriginal Controlled Medical Services (AMS), a trusted source for screening in Aboriginal communities, was seen as necessary to provide earlier detection. Participants reported Aboriginal people have positive experiences and form long-term relationships with their local AMS, where they have access to Aboriginal health workers. There was regret expressed by both groups at apparent lost opportunities for slowing disease progression and potentially avoiding ESKD.

A culturally appropriate predialysis pathway aimed at early inclusion of patients’ families and introducing a renal Aboriginal health worker/support role at diagnosis were acknowledged by the majority of participants as

key to engaging patients and families in slowing disease progression and minimizing emergency commencement of HD.

Flexible family-focused care

The role of family was recognized by both groups as vital to well-being for Aboriginal patients. Family was viewed as crucial to supporting treatment but also the cultural and extended family links that enabled this support. Health care providers were however challenged by patients prioritizing family over treatment, while recognizing flexibility in services as necessary to address Aboriginal family obligations. For example:

I just live day by day. I just thinkin of my kids all the time, that’s what keepin’ me goin’ seeing my boys, seeing the littlies. (Aboriginal woman, 30s)

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. (Dialysis nurse, 40s)

Additional home renal nurse support for Aboriginal people and their families to enable patients to dialyze at home was seen as key to keeping families and communities intact and providing flexibility. All participants felt this could reduce conflict between family and treatment obligations and improve “compliance” with treatment regimes.

Managing patient fear of mainstream services

Both participant groups described the fear and apprehension experienced by many Aboriginal renal patients, who had witnessed family members' suffering and early death on HD or from untreated ESKD. Patients were concerned about placing a high burden of care on their teenaged or young adult children, who were raising their own families. Several Aboriginal patients reported having been born in the mortuary of a local hospital in the late 1950s, when their mothers were not permitted to give birth in the maternity ward with non-Aboriginal women.

I was born in the mortuary of the . . . hospital, cause back in those days our mothers weren't allowed to birth in the maternity ward with all them white mothers. (Aboriginal woman 50s)

I think there's is an element of lack of understanding of the past policies that were in place where Aboriginal people were taken away from hospitals you know removed, the stolen generation and the grief and loss that associates with that. (Health worker, 40s)

Service provision shaped by culture

Both participant groups felt that the current cultural awareness training for clinicians failed to improve understanding of health care providers or effect system change. There needed to be a better way to educate health care providers about Aboriginality. Bringing patients and clinicians closer together in understanding and knowledge of each other was seen as the key to this. Aboriginal participants recommended replacing the current model of one day off-site training with renal patients and elders, who could deliver a more "informal" style of cultural education within renal units. They suggested elders could have informal on-site "tea room" chats with staff. This would build relationships, providing staff with opportunities to learn about Aboriginal culture in their own workplace through building sustained relationships with Aboriginal people. Staff also recognized the ineffectiveness of the current model provided locally, perceiving that in some instances, the 1-day training widened the gap in understanding. There was no follow-up or continuing access to cultural education. Health care providers also expressed frustration at organizational or institutional barriers to gaining increased cultural awareness and understanding.

But the nurses that we have, we see em every day, they should be more sensitive about who they're talking to and how they do it. And that's an important thing. (Aboriginal man, 50s)

We could all do with more cultural awareness in the workplace, but that comes from the culture of the organization. . . . the culture of the organization is at fault, not the culture of the individual unit. (Senior nurse manager, 40s)

DISCUSSION

Aboriginal patients receiving HD, and their health care providers, showed remarkable congruence of opinion on service provision. Both expressed common concerns about current service models, with consensus on the need for earlier screening to slow disease progression. Most participants identified the importance of an Aboriginal support person introduced at diagnosis, and an Aboriginal specific predialysis pathway. Patients and providers acknowledged multiple sources of fear of mainstream services as barriers to engagement with renal services. Some important differences between participants however are apparent. For example, Aboriginal patients emphasized the priority of family and relationships, which is in contrast to health care providers who viewed treatment and practical issues as paramount.^{12,21}

In contrast to previous work,^{12,13} our findings indicate considerable agreement between patients and health care providers on priorities for improving renal service delivery to rural Aboriginal people. Patients and providers concurred on the need for universal screening of Aboriginal people, through improved collaboration between AMSs and mainstream health organizations. Mainstream services require flexible, family-focused care that includes an Aboriginal specific predialysis pathway, supported by an Aboriginal health worker/support role. This may assist in slowing disease progression, and potentially avoid dialysis altogether. Once patients have ESKD requiring dialysis, providing increased renal nurse support to get more Aboriginal people onto home HD was recommended by patients and providers. Both participant groups also critiqued the current model of cultural awareness training provided for non-Aboriginal staff and said that this was not working.¹⁵

A separate predialysis pathway and a renal-specific Aboriginal health worker/support role to encourage Aboriginal CKD patients to engage with renal services could reduce expenditure and the social and emotional "costs" of the current system. The expense of universal

CKD screening for Aboriginal people could be offset by the savings of reduced acute admissions associated with late diagnosis and emergency commencement of HD. Early detection and management may slow disease progression, potentially avoiding the need of HD altogether for Aboriginal people with CKD.²² Late diagnosis of CKD and ESKD increases morbidity and mortality, resulting in longer and more expensive hospitalization.⁵

Hospital episodes for dialysis in Australia accounted for 44% of all hospitalizations for Aboriginal people from 2008 to 2010.²³ The cost of HD for Aboriginal people extends beyond fiscal to the impact on patients, families, and communities of the dislocation and emotional, physical, and spiritual suffering caused.^{24,25} In 2012, the Australian state within which the study was conducted identified “systemic change” as necessary in improving service delivery to contribute to “closing the gap” in Aboriginal health.²⁶ This is consistent with national policies and initiatives.^{27,28} It is also known that the responsibility for reducing health disparities for Aboriginal people “rests primarily with the healthcare system and its providers.”²⁹

Study participants wanted an increase in renal nurse support to enable more rural Aboriginal patients to access HD at home. Health system savings from one patient being dialyzed at home are estimated to exceed \$30,000 (Australian) annually, after an initial training cost of approximately \$15,000.³⁰ Studies have shown that home HD for remote Aboriginal patients increases compliance and self-care when patients are given responsibility for their treatment, resulting in better quality of life and outcomes.^{31,32} The savings from increasing the numbers of Aboriginal people on home HD could fund increased community renal nurse support and renal-specific Aboriginal support to encourage CKD patients to remain on an Aboriginal specific predialysis pathway.

A recent review of continuing high rates of kidney disease among Indigenous Australians argued that an urgent, comprehensive health care approach including primary prevention, is needed to address both the medical and socioeconomic dimensions of this major problem, given the high cost of tertiary level medical care.³³ An Australian Institute for Health and Welfare report shows Indigenous Australians having more advanced CKD at diagnosis, with higher hospitalization rates than the general population.³⁴ Given significant disparities in CKD rates between the Aboriginal and non-Aboriginal populations, with the incidence of treated ESKD among Aboriginal Australians projected to rise by 43% between 2008 and 2020,³⁵ universal screening is clearly urgent. Kidney Health Australia recommends annual screening for CKD

as part of an annual health check for Aboriginal populations.²² Doctors or AMSs can access Australian government health rebates for providing this service.²

Patients and providers cited instances of avoidance of mainstream health services by mothers in the past through fear of having their children “stolen” from them by welfare.¹⁵ Disclosure by several participants during interviews of that they were born in a hospital mortuary provides a powerful illustration of the ongoing fear and mistrust resulting in avoidance of mainstream services by Aboriginal people, being felt generations later.

Our study has limitations. Small sample sizes and sampling from only one region limits transferability to other areas. Using purposive sampling of health care providers and high response rates strengthened this study by including a diverse and broad range of perspectives and experience including key informants in regional services. Participation by 86% of the Aboriginal HD recipients in the region and 94% of invited health care providers within that region provides further strength to this work.

Mainstream health care organizations that do not understand or work with cultural difference are contributing to a form of institutionalized racism, resulting in cultural barriers to Aboriginal use of health care services.⁸ This study confirms an absence of cultural understanding within mainstream renal services that is perpetrated by system and organization structures, and less by individual or personal instances of racism and discrimination.

Current jurisdictional health policy where the study was conducted states that cultural awareness training is mandatory for all health staff and “gaining an understanding of disparities in health status for Aboriginal people is essential for creating positive change” (p. 1)³⁶. Despite this “mandatory” requirement, training places are limited. Both participant groups believed the overall efficacy or indeed appropriateness of training is problematic. A recent local audit of staff who had accessed training reported limited improvement in overall cultural awareness of non-Aboriginal staff, with evidence of overt racism among health employees.³⁷ The problem appears systemic, and less from individual shortfalls in cultural knowledge and understanding. Our data from 29 professional providers of care confirms this.

Until health systems accommodate Aboriginal culture and create environments and services that meet Aboriginal needs, disparities between Aboriginal outcomes from serious chronic disease will remain.²¹ Reducing financial expenditure on inefficient services for rural Aboriginal people with CKD requires economic modeling to design more acceptable and worthwhile investment in their treatment and care.

CONCLUSION

Patients and health care providers believe that current services are not flexible, optimally accessible, or family focused. Aboriginal specific services and support mechanisms need to be embedded within a redesigned system. This may not only provide services that are more effective and efficient, it is likely to be less “costly” to the system and certainly less “costly” to Aboriginal patients and family.

ACKNOWLEDGMENTS

We sincerely thank the Aboriginal HD patients in this study for contributing their experiences and perceptions. Without these, this study would not have been possible. We also thank Community Reference Group members who provided invaluable guidance throughout this study. Most of the Aboriginal participants and the Community Reference Group members are members of the Bundjalung Nation. We gratefully acknowledge the Bundjalung Nation, upon whose lands this research took place.

Conflict of interest: The authors have no conflict of interests to declare.

Manuscript received May 2014.

REFERENCES

- McDonald SP. Placing Aboriginal kidney disease in context. *Can Med Assoc J.* 2014; **186**:93–94.
- Australian Institute of Health and Welfare. The health and welfare of Australia's Aboriginal and Torres Strait Islander people, an overview, 2011. Canberra: AIHW 2011. Report No.: Cat no. IHW 42.
- Aspin C, Brown N, Jowsey T, Yen L, Leeder S. Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: A qualitative study. *BMC Health Serv Res.* 2012; **12**:143.
- Liaw ST, Lau P, Pyett P, et al. Successful chronic disease care for Aboriginal Australians requires cultural competence. *Aust N Z J Public Health.* 2011; **35**:238–248.
- Cass A, Cunningham J, Arnold PC, Snelling P, Wang Z, Hoy W. Delayed referral to a nephrologist: Outcomes among patients who survive at least one year on dialysis. *Med J Aust.* 2002; **177**:135–138.
- Durey A, Thompson SC, Wood M. Time to bring down the twin towers in poor Aboriginal hospital care: Addressing institutional racism and misunderstandings in communication. *Intern Med J.* 2012; **42**:17–22.
- Larson A, Gillies M, Howard PJ, Coffin J. It's enough to make you sick: The impact of racism on the health of Aboriginal Australians. *Aust N Z J Public Health.* 2007; **31**:322–329.
- Henry BR, Houston S, Mooney GH. Institutional racism in Australian healthcare: A plea for decency. *Med J Aust.* 2004; **180**:517–520.
- Paradies Y. *Race, Racism, Stress and Indigenous Health.* Melbourne, The University of Melbourne; 2006; 499. School of Public Health.
- Durey A, Wynaden D, Thompson SC, Davidson PM, Bessarab D, Katzenellenbogen JM. Owning solutions: A collaborative model to improve quality in hospital care for Aboriginal Australians. *Nurs Inq.* 2012; **19**:1–9.
- Chenitz KB, Fernando M, Shea JA. In-center hemodialysis attendance: Patient perceptions of risks, barriers, and recommendations. *Hemodia Int.* 2014; **18**:364–373.
- Harrington Z, Thomas DP, Currie BJ, Bulkanhawuy J. Challenging perceptions of non-compliance with rheumatic fever prophylaxis in a remote Aboriginal community. *Med J Aust.* 2006; **184**:514–517.
- Hasnain M, Connell KJ, Menon U, Tranmer A. Patient-centred care for Muslim women: Provider and patient perspectives. *J Womens Health (Larchmt).* 2011; **20**:73–83.
- Australian Institute of Health and Welfare. Aboriginal and Torres Strait Islander Health Services Report, 2010–11. Canberra, 2012.
- Rix EF, Barclay L, Wilson S, Stirling J, Tong A. Service providers' perspectives, attitudes and beliefs on health services delivery for Aboriginal people receiving haemodialysis in rural Australia: A qualitative study. *BMJ Open.* 2013; **3**:e003581.
- Richards L, Morse JM. *Read me First for a User's Guide to Qualitative Methods.* Thousand Oaks, Sage Publications; 2013.
- Bessarab D, Ng'andu B. Yarning about yarning as a legitimate method in indigenous research. *Int J Crit Indigenous Stud.* 2010; **3**:37–50.
- Kovach M. Conversational method in indigenous research. *First People Child Fam Rev.* 2010; **5**:40–48.
- Australian Institute of Health and Welfare. Projections of the incidence of treated end-stage kidney disease among Indigenous Australians, 2009–2020: A working paper. In: AIHW, ed., Canberra, 2011.
- Strauss AL. *Qualitative Analysis for Social Scientists.* New York, Cambridge University Press; 1987.
- McBain-Rigg KE, Veitch C. Cultural barriers to health care for Aboriginal and Torres Strait Islanders in Mt. Isa. *Aust J Rural Health.* 2011; **19**:20–27.
- Kidney Health Australia. *Chronic Kidney Disease (CKD) Management in General Practice.* Melbourne, Kidney Health Australia; 2012.

- 23 Steering Committee for the Review of Government Service Provision. Report on government services 2013: Indigenous compendium. In: Productivity Commission, ed. Canberra, 2013.
- 24 Burnette L, Kickett M. Dislocation and dialysis in Aboriginal patients with renal failure. *Aborig Isl Health Work J*. 2009; **33**:10–13.
- 25 Rivalland P. *It's More Than Machines and Medicine: They should Understand There's a Yanangu Way*. Darwin, Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation & CRCAH, Darwin; 2006.
- 26 NSW Ministry of Health. Towards an Aboriginal Health Plan for NSW: Discussion paper. North Sydney: NSW Health 2012.
- 27 National Aboriginal and Torres Strait Islander Health Council. National strategic framework for Aboriginal and Torres Strait Islander Health: Framework for action by governments, Canberra. 2003.
- 28 Office for Aboriginal and Torres Strait Islander Health. Family centred primary health care report. Canberra, Department of Health and Ageing, 2008.
- 29 Cunningham J, Cass A, Arnold PC. Bridging the treatment gap for Indigenous Australians. Demands for efficiency should not be met at the expense of equity. *Med J Aust*. 2005; **182**:505–506.
- 30 Cass A, Chadban S, Gallagher M, Howard K, Jones A, McDonald S, et al. The economic impact of end-stage kidney disease in Australia: Projections to 2020. Melbourne 2010.
- 31 MacGregor MS, Agar JWM, Blagg CR. Home haemodialysis—International trends and variation. *Nephrol Dial Transplant*. 2006; **21**:1934–1945.
- 32 Villarba A, Warr K. Home haemodialysis in remote Australia. *Nephrology (Carlton)*. 2004; **9**:S134–S137.
- 33 Stumpers S, Thompson N. Review of Kidney disease and urologic disorders among Indigenous people. Mount Lawley: Edith Cowan University 2013.
- 34 Australian Institute of Health and Welfare. Chronic kidney disease in Aboriginal and Torres Strait Islander people. Canberra: AIHW 2011. Report No.: PHE 151.
- 35 Milroy HM. Beyond cultural security; towards sanctuary. *Med J Aust*. 2013; **199**:14.
- 36 NSW Health. *Respecting the Difference: An Aboriginal Cultural Training Framework for NSW Health*. Sydney, NSW Health; 2011.
- 37 Franks T. *Aboriginal Cultural Awareness Training Evaluation*. Lismore, Clinical Education & Training Institute; 2011; 37.

SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Appendix S1 Case studies and semi-structured interview prompts used to guide health care provider interviews.