

Aboriginal patients driving kidney and healthcare improvements: recommendations from South Australian community consultations

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The health care needs of Aboriginal and Torres Strait Islander people have unique elements that require a specific response. While the challenges of living with chronic illnesses and needing to travel to receive care are also experienced by some non-Indigenous peoples, the additional impacts of colonisation, racism, intergenerational trauma, marginalisation and the socio-cultural determinants of health experienced by many Indigenous peoples are important considerations.¹

Aboriginal and Torres Strait Islander people often experience health impacts of illnesses such as kidney failure from a younger age, while still studying, working and raising children.² Across Australia, Aboriginal and Torres Strait Islander people are five times more likely to start dialysis than non-Indigenous Australians with kidney failure rates 10-30 times higher in remote areas.²⁻⁴ Within South Australia (SA), Aboriginal and Torres Strait Islander people represent two per cent of the total population, with 97% of this group identifying as Aboriginal, and 30% residing outside of Adelaide.⁵ Specialised healthcare is located in major cities, requiring many people to leave their homes and families to receive lifesaving treatment.

Health and kidney care services are increasingly recognising that Aboriginal and Torres Strait Islander people must be actively involved in designing new models

Abstract

Objective: To describe the experiences, perceptions and suggested improvements in healthcare identified by Aboriginal patients, families and community members living with kidney disease in South Australia.

Methods: Community consultations were held in an urban, rural and remote location in 2019 by the Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project and Kidney Health Australia. Consultations were co-designed with community members, using participatory action research, Yarning, Dadirri and Ganma Indigenous Methodologies. Key themes were synthesised, verified by community members and shared through formal and community reports and media.

Results: Aboriginal participants identified the importance of: family and community and maintaining their wellbeing, strength and resilience; the need for prevention and early detection that is localised, engages whole families and prevents diagnosis shock; better access to quality care that ensures Aboriginal people can make informed choices and decisions about their options for dialysis and transplantation, and; more Aboriginal health professionals and peer navigators, and increased responsiveness and provision of cultural safety care by all kidney health professionals.

Conclusion: Aboriginal community members have strong and clear recommendations for improving the quality and responsiveness of health care generally, and kidney care specifically.

Implications for public health: Aboriginal people with lived experience of chronic conditions wish to significantly inform the way care is organised and delivered.

Key words: Indigenous, community participation, health services research, co-design, kidney diseases.

of kidney care that meet their clinical and cultural needs.⁶ Previous SA studies have mapped individual kidney care journeys, identifying specific barriers and enablers in communication, collaboration and care.⁷⁻⁹

In 2018, the Aboriginal Kidney Care Together-Improving Outcomes Now (AKction)

project brought together Aboriginal kidney patients and community members, health professionals, health service managers, decision makers, academics and researchers to identify gaps and strategies to improve kidney care in SA.¹⁰ An AKction Reference Group (ARG) comprising Aboriginal patient experts and family members was established

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and supported by the AKction research team. The ARG and research team worked closely with Kidney Health Australia (KHA), the Central Northern Adelaide Renal and Transplantation Service (CNARTS) and other local community members to co-design and co-facilitate consultations in a metropolitan, outer regional and very remote location within SA. Working in partnership,^{11,12} meaningful Indigenous Governance, respectful collaboration, cultural safety¹³ and 'reimagining' gold-standard kidney care, underpinned this approach.

In this study we sought to include wider Aboriginal patient, family and community voices, and ensure their experiences and priorities influenced policies, guidelines and health service priorities and structures. Consultations were co-designed to inform local, jurisdictional and national health care, the writing of inaugural Kidney Health Australia (KHA) and Caring for Australians with Renal Impairment (CARI) Guidelines,¹⁴ and local and national initiatives involving Australia and New Zealand Dialysis and Transplant Registry ANZDATA,¹⁵ Kidney Health Australia¹⁴ and the National Indigenous Kidney Transplantation Taskforce.¹⁶

Methods

This paper reports on the findings of the consultations; the emerging themes and feedback from community members regarding current care experiences and suggestions for improvement. In South Australia, the First Nations contributors identify as Aboriginal Australians and prefer the term Aboriginal is used when referring to community members involved in the AKction project.

Study design, setting and participants

Participatory action research comprising repeated cycles of 'look and listen, think and discuss and take action together'⁸ was used to build relational networks and conduct the consultations in urban, rural and remote locations. ARG members, CNARTS and Aboriginal health staff, KHA staff and AKction researchers contacted Aboriginal renal patients, community members and regional health professionals to discuss the best consultation venues, timing around dialysis, transport support, catering and approaches to recruitment to maximise involvement. All of these groups were involved in recruitment using emails, verbal invitations, telephone

calls, flyers in health services, dialysis centres, hostels and support services.

Consultations were held in a major city, outer regional and very remote location across South Australia where the AKction project had existing relationships and ethics cover. Sites included: Kanggawodli Aboriginal medical hostel in Adelaide December 2018, Pika Wiya Aboriginal Health Service in outer regional Port Augusta in February 2019 and very remote Ceduna Hospital in June 2019¹⁷ (see Table 1). Participants (Aboriginal kidney care patients, family members, other community members who are carers) self-selected whether to attend consultations, on which days and for how long. Transport assistance was provided and sessions were timed around people's dialysis schedules as much as possible. The Kanggawodli consultation included both Aboriginal people who lived in Adelaide and Aboriginal people from rural and remote areas staying at the hostel while receiving specialist care for a range of health conditions. Health professionals adopted a support and listening role in all consultations, in a similar model to that used in Indigenous Patient Voices⁶ and Catching Some Air consultations.¹⁸

Data collection – consultation methodology

Each consultation began with a Welcome to Country by a Traditional Custodian and an introduction to the purpose and methodology led by the research team. Written participant consent for participation, audio recordings, identification in reports and photography was obtained. Indigenous methodologies: Yarning,^{19,20} Dadirri deep listening²¹ and Ganma knowledge sharing²² were used with prompt questions (see Table 2) in semi-structured focus groups. Community participants were invited to share their experiences of care and suggestions for improvement. Smaller round table discussions were facilitated by researchers and/or local health care providers (as participants preferred), followed by larger, whole group discussions. Conversations were recorded, and/or notes taken, as preferred by individual participants.

Data analysis

Key themes were identified, contextualised and prioritised by community members in a whole-group discussion at the end of each consultation workshop, ensuring community participation in early analysis and

prioritisation. All butcher's paper and group facilitation notes were transcribed written into site specific reports, checked by ARG and approved by participants in location to ensure accuracy, truth telling and community control.¹⁷ Permission to include names and images was sought from each participant, or family members if a participant passed away, and each participant or family representative received a final version. All raw data was then collated by two non-Indigenous researchers using NVivo 10 software. Emerging themes from prompt questions were combined to form the coding tree. Results were discussed with research team and reference group members.

Ethics approval was provided by the Aboriginal Health Research Ethics Committee (#04-18-796, the University of Adelaide (ID: 33394) and Central Adelaide Local Health Network (HREC/19/CALHN/45).

Results

A total of 46 Aboriginal community members and 37 health professionals, managers, coordinators and researchers (Aboriginal and non-Aboriginal) participated (see Table 1). Findings are reported to highlight community priorities and responses to the 'prompt questions' and are organised under four themes: The importance of family and community; Preventing and detecting kidney disease early; Better access to quality of kidney care; and, Workforce (see Figure 1). These themes reflect the concerns and priorities identified by Aboriginal patients, family and community members (participants). Participant quotes are identified by location of consultation: major city (MC), outer regional Australia (OR) or very remote (VR) (19) to highlight commonality and difference of experiences and suggestions across locations in South Australia. Strategies to address each of these themes, as suggested by participants, are summarised in Table 3.

Theme 1: The importance of family and community

Being well involves more than just health care – the role of Country, family, community

Participants spoke passionately about the importance of connecting with family, community and Country, particularly on their non-treatment and non-dialysis days.

It's difficult to keep our spirits up without spending time on Country and with our family and loved ones. (OR)

Going back to the bush is good for the heart and mind. (VR)

Maintaining these connections was considered as important as receiving health care and dialysis, and often misunderstood by Western health care providers (professionals and services). Participants reported limited acknowledgment of the complexities of journeys, and the unique struggles faced when separated from Country, family and community.

Many people come from home communities where we are leaders and have important roles and responsibilities. When we have to leave that behind to access treatment in the city . . . , we feel like rubbish, and we are treated like [these things] are unimportant. (MC)

The importance of actively involving family and community members in all stages of care and decision making was also highlighted. Often family members moved to be with patients and sought to be more actively involved in their care.

We moved here to support my uncle, but we need just as much support to know what we should be doing. (VR)

Community based strengths and resilience

Participants highlighted that 'we are more than our disease' (MC) and that alongside the challenges and struggles, lies strength and resilience. While kidney disease and dialysis profoundly impacts all aspects of their lives, strong family and community spirit, and supporting each other when treatment begins, and during the long, difficult journey that follows, is what enables them to survive. Some community members, spoke of the importance of personal and community agency.

We have to stop this dependence on other people to solve problems, people need to be empowered. (VR)

Others identified their desire to get back into employment and become more self-sufficient.

Now my illness (kidney disease) is more under control, I want to get back to work. (OR)

Many identified that while clinical staff and support services play a crucial role in treating kidney disease, community members provide advocacy, cultural support, empowerment and leadership.

Table 1: Location and details of consultations, and summary of attendees.

Location, date and details of location	Aboriginal patients, carers and family member participants	Co-facilitation & support roles
Major City: Adelaide Kanggawodli Aboriginal hostel November 2018 1 day workshop Metropolitan Adelaide has multiple hospital based, outpatient and satellite dialysis services.	18 Aboriginal patients, family members and carers from urban, rural and remote locations & one non-Aboriginal carer. This includes 2 AKction Reference Group members who both contributed and co-facilitated the consultation.	1 Renal AHP who co-facilitated 10 non-Aboriginal attendees including 3 researchers/co-facilitators, 2 renal nurses, 3 nephrologists, 1 EO NIKTT, 1 student.
Outer Regional: Port Augusta Pika Wiya Aboriginal Health Service February 2019 2 day workshop Port Augusta regional hospital has a 12 chair unit and provides dialysis for 27 Aboriginal patients (which is nearly a third of all 95 Aboriginal people receiving dialysis in SA) ANZDATA Pers Comm Dec 2020)	17 Aboriginal patients, family members and carers from rural and remote locations. This includes 1 AKction Reference Group member who contributed, co-facilitated and interpreted throughout the consultation.	1 Renal AHP who co-facilitated 11 non-Aboriginal attendees including: 4 researchers/co-facilitators, 1 local dialysis manager/renal nurse, 3 visiting nephrologists, 1 CEO KHA, 1 EO NIKTT, 1 Pika Wiya health professional.
Very Remote: Ceduna Hospital June 2019 2 day workshop Ceduna Hospital has a 2 chair dialysis unit providing dialysis for remote area patients.	10 Aboriginal patients, family members and carers from Ceduna and nearby remote communities.	1 Renal AHP and 1 Aboriginal researcher who co-facilitated 3 local AHPs. 9 non-Aboriginal attendees including 3 researchers/co-facilitators, 1 local dialysis manager/renal nurse, 1 visiting nephrologist, 1 DON/CEO of Ceduna Hospital, 1 local nurse, 1 NIKTT EO, 1 renal coordinator)

Notes:

Further details can be found in each community consultation report available on Kidney Health Australia website <https://kidney.org.au/get-involved/advocacy/yarning-kidney-consultations>

AHP: Aboriginal Health Practitioner/Professional

EO: executive officer, NIKTT – National Indigenous Kidney Transplantation taskforce.

CEO KHA: Chief Executive Officer, Kidney Health Australia

Table 2: Focus group prompt questions: experiences of care and suggestions for improvement.

Questions
1. What is your experience with kidney disease? a. What did you know before having kidney disease – did it come as a surprise? <i>Prompt questions for facilitators</i> What did people know before having kidney disease – did it come as a surprise for them? How could people's understanding of kidney disease, access to kidney care, and experiences of dialysis and transplantation be improved?
2. How could kidney care may be made better for you and your community? a. Access b. Information c. How and where care is provided? <i>Prompt questions for facilitators</i> What other supports are needed (for example transport and accommodation, peer support, resources). How could information about kidney disease and kidney care be improved? What would help improve; prevention of kidney disease, early detection of kidney disease, access to dialysis and health care, kidney care and transplantation, and cultural safety.
3. What are the best ways to communicate health messages and share information? <i>Prompt questions for facilitators</i> What would be the best ways to communicate kidney health messages to patients and their families and communities? (health education)
4. We teach doctors and nurses – what do we need to make sure we teach them about caring for you? <i>Prompt questions for facilitators</i> Staff communication, cultural awareness and cultural safety, responsiveness, appropriateness How do people feel in interactions with staff?

Table 3: A summary of strategies identified by community members across all three sites.**Theme 1: Recognise the importance of families and communities****Recognise the vital role of family, community and Country**

- Help us keep up connections – they are vital for health and wellbeing
- Support us to return to family, country and community on non-dialysis days
- Recognise the important role that Aboriginal kidney patients play in their communities
- Actively involve family members in kidney care and decision making

Recognise community based strengths and resilience

- People with kidney disease are more than their illness
- Family, community and culture help people thrive rather than just survive
- Personal and community agency and self-sufficiency are important aspects, alongside kidney health care

Theme 2: Work with us on preventing and detecting kidney disease early**Help prevent kidney disease by increasing kidney health information**

- Focus information and education on 'knowing your kidneys, keeping your kidneys healthy, treatment options, healthy eating'
- Provide programs for young people in schools, families in community and primary health care
- Co-design prevention and knowledge sharing approaches with us: yarnning sessions, sharing stories, cooking classes, family fun days, family camps

Earlier detection of kidney disease

- Make it easier for community members to access kidney health checks
- Listen to and encourage family members to have check-ups, and act on any symptoms
- Recognise people with lived experience of kidney disease are a major source of information for family members
- Make kidney disease checks a routine part of annual health check and chronic conditions checks
- Recognise the shocking impact of late stage diagnosis and rapid transfer to hospital for emergency treatment
- Support people who are fearful and overwhelmed, encourage them to engage with early kidney care

Theme 3: Kidney care our way – improve our access and the responsiveness of care**Support us to access care in ways and places that we need**

- Use and/or develop information and resources that are visual, face to face education, videos, and in first language when possible
- Information should be delivered by Aboriginal patient experts – people with lived experience of kidney disease and dialysis, and culturally safe health professionals
- Provide more information about options before people start treatment
- Increase access to allied health and support professionals, including dietitians, exercise physiologists and mental health professionals, particularly in regional and remote areas
- Increase rural and remote dialysis and other treatment options

Recognise that what impacts our lives, impacts our ability to access kidney care

- Increase transport and accommodation options that are affordable, accessible and family friendly
- Support people to travel and return to Country and family, using the renal bus and 'holiday' dialysis

Recognise that we are juggling multiple health priorities

- Recognise that attending multiple appointments around dialysis is difficult
- Don't fill dialysis free days with other health appointments
- Health professionals could visit patients during dialysis – make it a 'one stop shop'

Improve the path to transplantation for patients, and support our families

- Clearer information about kidney transplantation work up processes and requirements
- Increase support to get onto transplantation list
- Increase support for family members during transplantation including workup and follow up
- Ensure community members understand that transplantation is a treatment, rather than a cure, and that they need to follow up on medication and self-care

Focus your policies, funding and guideline writing on what is important for us

- Many of us are on land and community councils and understand the importance of clear and meaningful policies and funding – these need to focus on our key priorities
- Kidney health needs to be recognised as a priority so that more kidney health and support services are provided
- Guidelines should focus on our holistic health needs, as well as prevention, risk factors, treatment options and follow up

Theme 4: Workforce**We want to see more Aboriginal people in the workforce and receive care delivered by our own people**

- Increase Aboriginal workforce in all areas of care, in all locations, and in dialysis specifically
- Increase access to interpreters to prevent miscommunication and enhance informed consent

We need peer support and peer navigators

- Increase peer support programs, and peer navigators – we need to be supported and guided by people who know what it is really like

Increase cultural training and responsiveness of all renal health professionals

- Increase cultural (awareness and cultural safety) training for staff
- Increase support and understanding of patients in view of their unique challenges
- Support us to remain connected to culture and community while undergoing treatment

Theme 2: Prevention and early detection**Preventing disease and providing health information in ways that work for Community**

Aboriginal patients and family members identified a need for increased access to information about kidney disease, prevention, progression and its impact on people's bodies and lives. They perceived that health practitioners had a key role in encouraging routine checks and providing more information about warning signs, early symptoms, management, treatment, and how to keep healthy. Community members suggested educational campaigns be developed nationally and adapted locally to enable a deeper understanding about kidneys and how to keep them healthy. They emphasised working with young people and children to prevent kidney disease and failure.

Kids gotta understand that you need to be healthy now to be healthy. (VR)

Getting into schools, raising awareness and getting kids thinking about their kidneys and how to keep them healthy. (OR)

Education in schools and community-based education involving cooking classes and blood pressure monitoring were suggested. Community members themselves would need to be involved in co-creating and co-delivering this education to ensure effectiveness.

Hold events that bring the community together to learn about keeping themselves healthy, [such as] cooking or health check days. (VR)

We need more information about what is happening, where to go for help and when to do this. (OR)

Pictures and diagrams should accompany any written information, and education could be delivered via television and social media, in a range of Aboriginal languages, to increase access, equity and decolonisation.

There are materials in Italian, Greek and other languages, but there is nothing in our languages – yet we are the Traditional owners of the land. (MC)

Earlier detection to prevent the shock of diagnosis

In each consultation, participants suggested having a specific campaign that encouraged and facilitated kidney health checks to enhance early detection. They discussed with concern the lack of knowledge about testing.

We don't know when it is best to get further information or a 'kidney health check', or even how to do this. (OR)

Repeatedly, participants identified that it was family members who provided information, and advised them to get their kidneys checked when certain signs and symptoms appeared.

I only knew what to look out for after seeing other family members with the same thing. (OR)

Community members discussed that kidney health checks should be part of the adult and child health check and /or chronic disease prevention and management.

Aboriginal Medical Services only focus on one disease, but do not include kidneys, dialysis, diabetes, etc. – they could be teaching about other organs while teaching about the eyes or something. (MC)

Earlier detection also enables discussion of options and preparation before treatment or dialysis began.

Patients and family members repeatedly spoke of late-stage diagnosis, rapid transfer to hospital and emergency treatment, of being alone, separated from family and Country (the lands, waterways and seas to which they are connected culturally and spiritually²³) and feeling rushed, shocked, acutely unwell and unable to mentally process or accept their diagnosis.

I was shocked when the doctor rang me to say I should start dialysis the next day. (MC)

When my kidneys are sick, I can't think straight. (OR)

When I found out my kidneys were sick, I didn't want to listen to the doctors, information just went in one ear and out the other. (VR)

The overwhelming fear of being diagnosed with kidney disease was repeatedly raised. A diagnosis of kidney disease (which is treatable) was often perceived as kidney failure (too late to treat). For those in rural and remote areas, kidney disease was seen as something that makes you leave family, Country and community, perhaps never to return.

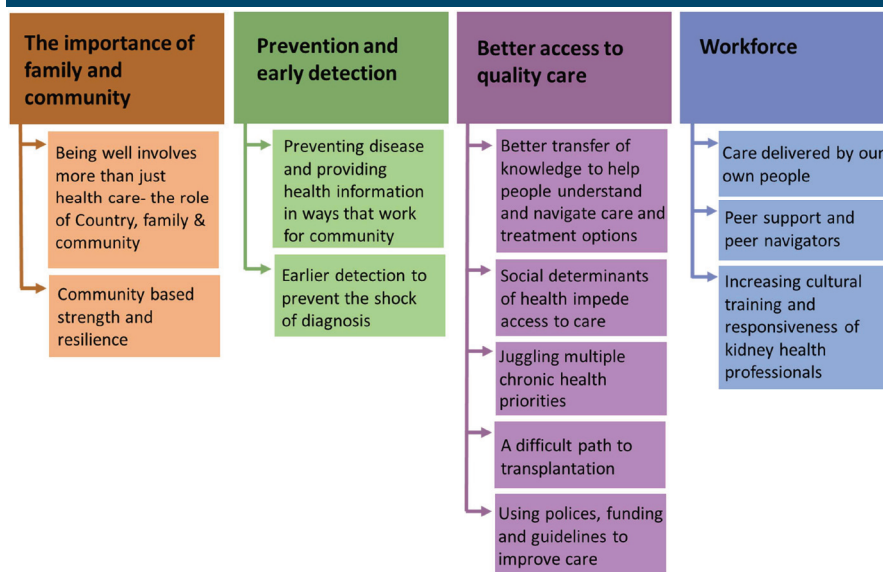
Kidney failure is scary, we know that it can be a death sentence or mean that you'll be stuck on dialysis for the rest of your life. (MC)

Theme 3: Better access to quality care

Better transfer of knowledge to help people understand and navigate care and treatment options

Community members want to know more about kidney care and treatment options.

Figure 1: Emerging themes.



Many participants received little information prior to commencing treatment (usually haemodialysis) and were confused about management and treatment options.

I want to know more about [the medications] I am taking, about dialysis and my options. (OR)

A significant number of participants experienced emergency admissions and immediate haemodialysis commencement via a central line. This limited opportunity or time to consider home-based dialysis, which takes substantial pre-planning. There was significant community uncertainty regarding the safety, effectiveness and feasibility of home haemodialysis or peritoneal dialysis, including concerns about the burden placed upon their family.

I know someone who used the bag [peritoneal dialysis]... they kept getting infections. It was no good. (VR)

Is peritoneal dialysis something I can have? I don't know. (OR)

Social determinants of health impede access to care

Issues surrounding transport, housing and temporary accommodation were raised repeatedly in each consultation. Challenges were amplified when relocating to city, regional or remote towns for specialist care and ongoing dialysis.

Some people are homeless. (all locations)

A lot of people are in hardship, the pension isn't enough, if we have to pay to travel there isn't enough left to get food. (OR)

Participants shared stories of the struggle to find somewhere safe and affordable to

live whilst undergoing dialysis, having to walk to and from treatment when there was no transport available, and missing dialysis due to these difficulties. Limited access to allied health professionals such as dieticians, exercise physiologists and other support professionals arose for those living in more remote areas.

Unless you are in the big hospital, you don't get the services. (VR)

The need for comprehensive mental health care, in collaboration with other clinical care, throughout all stages of the care journey was also emphasised.

That is when depression starts because you don't know what is happening. I used to work, but I don't anymore, I was exhausted, tired. Sunday was my only day off, because I attended dialysis for 5/6 hours a day, three times a week. (OR)

Participants identified an overall lack of access to dialysis chairs. One participant living semi-permanently in a city hostel, slotted into gaps in existing dialysis schedules, across a range of sites.

I never know what hospital I will be going to or whether I will be in the morning or afternoon, they just ring and say the transport will be here in 20 minutes, it makes it impossible to do anything else with my day. (MC)

Dialysis schedules ruled people's lives and access to 'holiday' chairs was limited. Many participants yearned to travel, visit family and Country, and be with others during Sorry Business (funerals and grieving) and cultural events.

I am a country man, I need to be able to move and travel to keep myself healthy. (Remote)

As if the pain from the kidney machines isn't bad enough, we already broken hearted from being away from home. (OR)

Others just wanted something to look forward to.

We can't go home, we can't go anywhere, we get trapped. (MC)

Juggling multiple chronic health priorities

Many Aboriginal kidney patients juggled multiple chronic health conditions alongside kidney disease. They described struggling to attend numerous appointments in different locations, and the difficulty in managing multiple illnesses and health professional recommendations. Dialysis free days were consumed by appointments, leaving patients with little time away from health services. Participants preferred health professionals to attend dialysis.

They could come to us while we are on dialysis. (MC)

A difficult path to transplant

Kidney transplantation is a pathway to getting one's life back. However, participants struggled to get on the waitlist, keeping track of multiple appointments, 'waiting for the call' and putting their lives on hold, for months or years. There was widespread uncertainty and confusion about the workup process, clinical requirements and support available to navigate numerous appointments across multiple services and sites. Meanwhile, life continued and funerals and 'sorry businesses' interrupted their workup.

They just told me that I had to lose weight to stay on the transplant list, not how much weight or why just that I had to. (MC)

There's a real panic, must always have your phone on and charged and in reach, can't let the grandkids play with it in case they decline that call. (OR)

Participants identified the importance of family being nearby throughout the journey and the need for increased financial and emotional support to enable this.

I put off going for transplant two times when I got the call, because I had heard from other community members how scary it was. (OR)

Transplantation was a massive experience for family members, but little support was available.

I was told you better say goodbye before surgery, just in case they (live donor and

recipient family members) don't come out – as a family we were offered no support, I felt useless like I wasn't a part of the journey. (OR)

Using policies, funding and guidelines to improve care

Community participants, many of whom are experienced land and community council members, recognised the need for policies and funding to increasingly and systematically support people experiencing kidney disease.

Cancer council have a bus and a hostel, I have stayed there before when my sister was sick, why can't we have something like that too? (OR)

Participants identified the importance of ensuring the inaugural CARI clinical guideline included more comprehensive information about the way health care can be organised and delivered to better support their wellbeing, address risk factors and challenges, and increase family-based decision making. Community members wished to be involved throughout the writing and implementation processes to ensure that the final guidelines appropriately represented their needs and priorities and could bring positive change.

Theme 4: Workforce

Care delivered by our own people

Increased Aboriginal workforce in all areas of care, in all locations and in dialysis specifically was sought:

We should educate our young people, they could become nurses and doctors and go back to community and work in renal care. (MC)

... our own people, working here, living here... not different people coming and going. (VR)

Increased access to interpreters to address miscommunication and confusion, as well as informed consent was also identified.

Peer support and peer navigators

Participants in each consultation identified the need for peer education and support, and that they would benefit enormously from having someone 'who knows how it feels' to accompany them on their journey. Many participants identified family members 'who had been through it (kidney care) before' who became their greatest source of comfort, knowledge and support. Peer support was needed when beginning dialysis, a new treatment, transplantation workup, or when

journeys became increasingly complex. This was discussed at length in the urban based meeting, by Aboriginal people living locally and those visiting from rural and remote areas for treatment.

I reckon [Aboriginal lived-experienced kidney patient] sharing her experience would be good – hearing about what other people have gone through would be really helpful. (MC)

The hospital should employ an [Aboriginal person with lived of kidney disease] to explain to Aboriginal people about dialysis and what is a kidney transplant, and the consequences of these treatments. (MC)

Increasing cultural training and responsiveness of renal health professionals

The necessity of increased cultural training for nurses and health professionals was raised in each consultation. Some participants referred to cultural awareness and cultural safety training;

People don't need to know specifics, they just need to be aware that diversity is out there and that it needs to be acknowledged. (OR)

Others sought deeper, two-way, respectful relationships that could be strengthened over time. Participants wanted staff to have better understanding of their personal challenges, particularly when relocating.

Moving to Adelaide is confusing, it is very different from the country. You have to learn about the buses and where the supermarkets are, all that extra stuff. (OR)

They sought support to remain connected to their culture and communities whilst undergoing treatment, for some, doing painting and artwork while on dialysis helped.

Discussion

The process undertaken by AKAction ARG and research team members, CNARTS and KHA to co-design community consultations has enabled Aboriginal patients, families and community members to discuss their experiences of kidney care and identify specific clinical, social, cultural and cultural safety priorities, gaps and strategies. The consultation process developed in SA has been used to inform the remaining KHA consultations around Australia.¹⁷ Similarly, NIKTT have utilised the ARG and consultations processes to form Indigenous Reference groups and consultations nationally,²⁴ enabling kidney care services to more effectively partner with consumers.^{11,25}

The consultation reports, verified by participants and shared with local, jurisdictional and national health services, have triggered kidney care changes within in South Australia, including the piloting of dialysis chairs in an Aboriginal hostel. AKAction subsequently held two key stakeholder workshops focusing on transport and accommodation, Aboriginal workforce and dental care.

The themes emerging in these consultations reflect those reported in many other Australian kidney care studies over the last fifteen years, including: the importance of family and community^{15,26} and their inclusion in care and discussions,²⁶⁻²⁸ the need for (improved) communication, prevention and earlier detection,^{15,26-29} the impacts of social determinants of health^{15,26} and juggling multiple chronic health priorities,²⁶ and the need for increased support to access to quality care,^{26,27,29} improvements in the pathway to transplantation^{15,16,28}; and the need for more Aboriginal workforce^{15,26,28,29} and improved cultural safety of staff and services.^{15,26,28} The suggestions of using policies, funding and guidelines to improve kidney care was also raised in the three Catching Some Air project sites - Darwin, Alice Springs and Thursday Island (18). This study, strengthens the findings of previous study, strengthening the argument for change. It provides localised examples and ensures that the voices of Aboriginal people from South Australia can also directly inform the new national clinical guidelines, and national agenda for improving kidney care.

Limitations

While recognising that these consultations with self-selected participants in three locations do not reflect all experiences and diversity of all Aboriginal South Australians, shared concerns were raised in each location indicating common elements across communities. Transport and language interpretation were provided to improve access and equity, and consultations were timed around dialysis sessions as much as possible, but some potentially interested participants could not attend. The pre-determined prompt questions may have limited discussion; these questions were reviewed following each consultation in response to community feedback, and wider, community-driven discussions were encouraged at each consultation.

The consultation was a learning process. The research team were largely non-Indigenous and included clinicians new to two-way learning and participatory action research approaches. Participating in workshops increased their personal and cultural awareness and critical reflection, and introduced them to decolonising concepts. Aboriginal community members with lived experience of kidney disease and Aboriginal health professionals co-planned and co-facilitated the consultations and small group discussions, ensuring the processes and settings were culturally welcoming and appropriate.

Conclusion

These consultations reinforce the value of community leadership to inform tangible changes and improvements in health care generally and kidney care specifically. When Aboriginal patients are recognised as experts in their own care, the unique, complex and multidimensional insights they and their families provide are invaluable. They can comprehensively inform local, jurisdictional and national health care co-design, policies, guidelines and standards. Meaningful involvement of Aboriginal people in the co-creation of care is necessary to ensure health knowledge and care is accessible, effective and responsive to needs.

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