A pilot place-based renal dialysis model of care responding to Aboriginal and Torres Strait Islander priorities in South Australia

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Submitted: 29 June 2023; Revision requested: 26 September 2023; Accepted: 1 November 2023

Key words: Aboriginal and Torres Strait Islander, kidney disease, cultural safety, co-design

Aboriginal and Torres Strait Islander renal health

Aboriginal and Torres Strait Islander (hereafter, respectfully, Aboriginal) families, communities and societies have thrived across Australia for millennia.[1] Yet, historical practices and the policies of Australian and jurisdictional governments since colonisation have contributed to disparities in health and social outcomes experienced by Aboriginal communities in contemporary Australia.[2] For example, Aboriginal people experience a much higher burden of chronic disease.[3] This includes higher rates of chronic kidney disease (CKD), with almost one in five Aboriginal adults showing biomedical signs of CKD in Australia.[4] Mortality rates for kidney disease are 3.9 times higher for Aboriginal people than the non-Indigenous Australian population.[5]

Dialysis care is the leading cause of hospitalisation for Aboriginal people at 12 times the rate of non-Indigenous people.[4,6] Among Aboriginal people with end-stage kidney disease, 87% were reliant on dialysis and only 13% had received a kidney transplant, as of December 2017, in comparison to 39% of non-Indigenous people who underwent dialysis and 51% who received a kidney transplant, illustrating disparities in treatment.[7] In South Australia, nearly 60% of all Aboriginal and Torres Strait Islander people registered with Central Northern Adelaide Renal Transplant Services (CNARTS) are dislocated from home, country, and community, compared to 6% for non-Indigenous patients, affecting dialysis attendance and associated complications from missed treatments.[8] The significant numbers of Aboriginal dialysis patients residing in urban hostels across Australia indicates the importance of exploring effective models of care for those who relocate for treatment.

The Australian healthcare system is built on colonising concepts of health, dominated by biomedical values. These cultural assumptions, focusing on disease and economic efficiencies, contrast with Aboriginal knowledge systems, which more strongly emphasise collective cultures and connections to people and environments.[9] Providing dialysis in a culturally safe environment, as defined by patients themselves, can reduce isolation, increase access, provide patient-centred care, and reduce missed dialysis sessions.[10] Therefore, addressing cultural safety is critical to achieving improvements in Aboriginal and Torres Strait Islander healthcare.[9]

Potential solutions for improving health outcomes with Aboriginal people are often well understood by the communities who experience health conditions directly.[11] This highlights the importance of co-designing health initiatives with Aboriginal individuals, families and communities.[12] Developing models of care for kidney health are more likely to align with best practice methods when they actively engage Aboriginal community members who have lived experience of kidney disease to co-design both the model and its key elements, as well as to inform evaluation processes to determine what is important as a patient, carer and family member when receiving that model of care.[13]

A recent study, the Aboriginal Kidney Care Together Improving Outcomes Now (AKction) research project, identified that patients and carers prefer to access dialysis services closer to home and within culturally safe and responsive environments.[10] In response to these findings, an urban hostel-based model of care was developed and piloted at Kanggawodli, a primary health care and accommodation service providing culturally responsive services for Aboriginal patients from country locations requiring tertiary care in metropolitan

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Aust NZ J Public Health. 2023; Online; https://doi.org/10.1016/j.anzjph.2023.100107

Adelaide. The name, Kanggawodli (pronounced GANG-ga-*wod*-lee), is a Kaurna word meaning 'caring house'.

An Aboriginal model of care for renal dialysis

The dialysis model of care at Kanggawodli was developed in partnership with Northern Adelaide Local Health Network (NALHN), Central Adelaide Local Health Network (CALHN) and Aboriginal community members with lived experience of CKD from the AKction community reference group, who strongly advocated for its establishment. CALHN provided the clinical workforce and expertise, while NAHLN funded capital items and infrastructure redevelopment. Dialysis services were offered to those clients experiencing complexity who were currently staying at Kanggawodli and receiving dialysis at a local urban hospital. Kanggawodli's ethos is to create a home away from home environment for Aboriginal patients and their carers when having to travel to Adelaide for healthcare. This urban hostel-based model of care provides an opportunity to deliver services in a family-centred way, which aligns with Aboriginal ways of being and knowing, as patients can have family members visit and remain on-site whilst they are dialysing.

The pilot offered four people dialysis at Kanggawodli, three times a week, provided by an Aboriginal Health Practitioner and a renal nurse, in addition to opportunistic wrap-around Allied Health care services (e.g., podiatry). Flexible scheduling encouraged the participation of patients who had been identified as high risk or as failing to meet their recommended clinical time on dialysis. If a consumer was unable to attend their session, there was the flexibility to swap morning and afternoon times with other patients to suit individual needs. Similarly, when scheduled patients were unable to travel to Adelaide for their planned dialysis, other patients were given the opportunity to dialyse at Kanggawodli instead of the hospital, with a waitlist of patients who expressed a wish to dialyse at Kanggawodli. In this way, patients were empowered to take more control of their care by individually negotiating changes to their scheduling then advising staff of the changes. The pilot aimed to support patients with complex needs to complete dialysis care more thoroughly than their previous hospital attendance had indicated.

Consumer and provider perceptions of the model of care

Demographics

Participants in the pilot included four consumers of renal dialysis services, all of whom were aged between 50-60 years of age. All were from regional and remote locations and were residing at Kanggawodli and receiving dialysis services at an urban hospital while waiting for more permanent accommodation. Three of the participants were female and one was male. In addition, three service providers also provided feedback on their experiences of the model of care.

Consumer perceptions

All patients reported positive experiences when receiving dialysis services at Kanggawodli. Patients felt culturally safe and respected by health care professionals, which created unique opportunities to increase the health literacy of both patients and their families, especially their understanding of the impacts on health outcomes of shortening treatments. This finding was also supported by health professionals, who described the service as more culturally responsive and able to meet patient needs than many hospital environments. All patients indicated that the environment at Kanggawodli was more comfortable than hospital settings to complete dialysis, particularly as they could have family visits, talk with other residents and staff or watch television, none of which are consistently available in hospitals.

Patients designed their own dialysis schedule to help meet their social and community needs. Several patients were well-known artists and regularly attended a nearby Aboriginal art studio and gallery. Being able to have a dialysis schedule which helped meet their needs to attend the gallery to paint, attend exhibitions and other community engagements had a positive effect on well-being.

Receiving an increase in their dialysis schedule resulted in improved quality of life for patients. It enabled service providers to support patients to have planned trips to their home community and country. Patients frequently returned to Adelaide feeling emotionally and physically better, with their spirits lifted by being able to see family and be reconnected to their country, even if only for short periods of time. One consumer has successfully returned to country on two occasions to visit family. Multiple patients have been able to have treatment at Kanggawodli while waiting for accommodation in community.

Provider perspectives

Service provider responses indicated increased satisfaction as a result of being able to provide high-quality, culturally responsive care. The model provided a space for the Aboriginal Health Practitioner and renal nurses to develop an understanding of an individual patient's context and their individual requirements, allowing clinicians to tailor care and specific health literacy to meet the individual needs of patients. This often had not been able to be achieved in larger hospital settings due to demands on resources and staff. Providers indicated that the program created a learning space where non-Aboriginal clinicians could build on their cultural awareness and responsiveness in a safe space.

Several providers reported an increase in their cultural knowledge, which influenced their daily actions in ways that had not been identified or emphasised in previous training courses. Non-Aboriginal clinicians described how their individual cultural awareness and knowledge increased by having the opportunity to work alongside Aboriginal patients and clinicians.

Providers were asked to rate the effectiveness and quality of the renal dialysis program at Kanggawodli. All providers agreed the service met or exceeded best-practice standards across a variety of areas, including nutritional options for patients; access to clinical services such as specialists and medications; access to other services within local Aboriginal primary health care services; social and emotional well-being of patients; flexibility of dialysis treatment; empowerment and quality of life; and rapport and communication between health providers and patients. Several providers asserted that the service model provided adequate flexibility to provide patient-centred care, which is not always possible in a hospital setting.

Delivering care in an urban hostel setting provided an environment that was more focused on individual needs and care, which is not always achievable in an acute setting. All clinicians and health professionals interviewed clearly identified that there was an increase in participation with patients meeting their minimum dialysis

Table 1: Consumer and provider quotes regarding the Kanggawodli renal dialysis model of care.

Consumers
"It means a lot being able to have family keep me company and yarn to them. Makes me feel great just having other Aboriginal people around to yarn to and say hello, makes me happy". (Consumer A)
"Stay with family. Sitting here yarning, laughing, thinking, watching, make me happy inside". (Consumer B)
"At Kanggawodli my family are here, we are all together. But only my brother is there with his wife who is dialysing at [a nearby hospital]". (Consumer C)
Providers
"The set-up at Kanggawodli allows you to focus all attention on the patients you are caring for. As a clinician, I feel I have greater opportunity to get to know each individual and can work according to clinical guidelines". (Provider A)
"As a long-term health professional providing renal services, I have never seen the benefits of a new model of care so quickly come to fruition with both patients and staff". (Provider B)
"My learning curve has been vertical, from a cultural perspective. Since being here, I would say my understanding of cultural requirements and needs has come on 1000-fold. I have done all the cultural learning courses, but it doesn't prepare you for what you're actually learning in this environment". (Provider B)

requirements due to the flexibility of the service. This included the ability to watch television or engage with family and other residents while receiving treatment.

Examples of consumer and provider reflections are presented in Table 1.

Discussion

Receiving dialysis services in a hospital setting is often an isolating experience for Aboriginal people, with limited opportunities to establish meaningful relationships with staff, and limited ability to access family support. The Kanggawodli renal dialysis model of care supports the building and maintaining of strong partnerships between primary health care services, allied health services and acute clinicians. This allowed the provision of wrap-around services and screening, which resulted in greater patient experiences and compliance with safety and clinical standards, including the meeting of National Safety and Quality Health Service Standards for Aboriginal health.[14] The effectiveness of this model of care suggests that delivering services in proximity to where patients are living removes barriers of access, transport and competing commitments through flexibility of scheduling.

The success of the Kanggawodli renal dialysis model of care, from an Aboriginal community perspective, has increased the community's expectations of what is possible for people experiencing dialysis treatment. It has created community demand for a model of this nature and has introduced the possibility for this type of model to be offered closer to home for Aboriginal people. To ensure the success of such programs, it is important to ensure Aboriginal health professionals are trained to be able to provide dialysis services closer to home, including in regional locations.[10] This aligns with findings from Kidney Health Australia's consultations in 2020, which identified a need to ensure Aboriginal health professionals are trained to be able to provide dialysis services closer to home, with a significant demand and increasing need identified in regional and remote parts of South Australia.[15]

Conclusion

Service delivery within existing cultural frameworks, as part of holistic care, increased patient participation in dialysis treatment as a result of the model of care. Providers were able to deliver individualised education tailored to patients' needs, which increased patients' and carers' understanding and health literacy, as well as the importance of meeting clinical guidelines for their treatment plans. This re-empowered patients in self-management of their chronic conditions and provided more flexibility in delivering care. Patients were able to negotiate their dialysis timeslots with other patients dialysing at Kanggawodli to suit competing health, social and family needs.

This urban hostel-based model of care was developed to support the cultural needs of the patient cohort and was responsive to the unique needs of its patients. The model provided dialysis in an environment that enabled patients to interact with family and other residents during their treatment. The provision of patient-centred care at Kanggawodli resulted in a safe physical and cultural environment for Aboriginal patients receiving dialysis. This improved patients' relationships, social connectedness, and engagement amongst each other, with health professionals and other allied health services. It is also an example of holistic pragmatic care as articulated by the 1989 National Aboriginal Health Working Party which described 'health' from an Indigenous perspective as "a matter of determining all aspects of their life, including control over their physical environment, of dignity, of community self-esteem and of justice".[16]

Funding

The South Australian Health and Medical Research Institute acknowledges that this has been funded and supported by the Government of South Australia through the Department for Health and Wellbeing. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Government of South Australia.

Ethics statement

Ethics applications were approved by the Aboriginal Health Research Ethics Committee of South Australia, NALHN Research Governance Team and the CALHN Executive Research Committee.

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Conflicts of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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