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The Role of Aboriginal Kidney Health Mentors in the Transplant Journey: A Qualitative Evaluation

Sophie Pascoe[1] | David Croker[2] | Lachlan Ross[2] | Peter Henwood[2] | Neil Wilkshire[2] | Cedrina Algy[2] | Selina Bob[2] | Heather Hall[2] | Michelle Misener[2] | Gillian Gorham[1]

[1]Wellbeing and Preventable Chronic Disease Division, Menzies School of Health Research, Casuarina, Northern Territory, Australia | [2]Panuku, Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (Purple House), Darwin, Northern Territory, Australia

Correspondence: Sophie Pascoe (sophie.pascoe@menzies.edu.au)

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ABSTRACT

Issue Addressed: Whilst Aboriginal and Torres Strait Islander people in Australia experience disproportionately high rates of chronic kidney disease, they have lower rates of kidney transplantation and face many barriers to accessing culturally safe health care. Aboriginal kidney health mentors with lived experience of transplantation have been proposed to improve the patient journey and increase health promotion, but there has been limited evaluation of the role of mentors.

Methods: A qualitative evaluation of the 'Hunting Kidney Transplant' patient mentoring project implemented by Purple House in the Northern Territory involved in-depth interviews, focus groups and participant observation with Aboriginal kidney health mentors and renal staff. Data analysis methods included inductive thematic coding and collaborative synthesis of emerging themes with Aboriginal co-researchers.

Results: Aboriginal kidney health mentors play a holistic and multi-directional role helping people to navigate the transplant process. The role of mentors encompasses both visible and invisible work and is centred on a 'Right Way Working' approach, including building trust, respect and taking time during the work-up period. Key enablers include kinship and community connections and ongoing support from Purple House. Key barriers include COVID-19 and institutional racism within the mainstream health service.

Conclusions: Aboriginal health mentors with lived experience of chronic conditions can play an important role in supporting people and promoting cultural safety in health services.

So What? Further support and funding are needed to develop, evaluate and embed the mentor role into policy and practice to improve patient journeys, health promotion, transplant rates and health outcomes.

1 | Introduction

Chronic kidney disease (CKD) disproportionately impacts on Aboriginal and Torres Strait Islander people in Australia, and people in rural and remote areas, like the Northern Territory (NT), face additional barriers to accessing appropriate health care [1]. Whilst kidney transplantation can improve life expectancy and quality of life for people with end-stage kidney disease (ESKD), there are notable inequalities in terms of who can access kidney transplants and many barriers to being able to complete pre-transplant work-up [2]. Although Aboriginal and Torres Strait Islander people in Australia have higher rates of ESKD, they have lower rates of kidney transplantation. In 2017, Aboriginal and Torres Strait Islander people made up 12% of new patients beginning ESKD treatment in Australia, despite comprising just 3.3% of the population [3]. In the NT, the incidence of treated ESKD for Aboriginal people is nine times the national average [4]. However, research indicates that Aboriginal and Torres Strait Islander people receive transplants at approximately one-third the rate of non-Indigenous Australians and wait longer to receive a transplant [2].

Many barriers exist to improving Aboriginal and Torres Strait Islander transplant rates, including limited access to information and resources, lack of culturally appropriate health promotion and difficulties in understanding and completing work-up requirements. [5, 6] For people with kidney disease in general, patient information may be inappropriate for culturally and linguistically diverse Aboriginal and Torres Strait Islander communities [7].

In the NT, patients must travel to Adelaide to receive a kidney transplant. Majoni et al.'s research in the NT indicates that delays in kidney transplant waitlisting for Aboriginal people were often caused by communication barriers, access and ability to navigate complex pathways to specialist services [8]. Hughes et al.'s study of kidney care also reveals that poor communication between consumers and health professionals are a key barrier to optimal care, with one-third of participants reporting difficulty understanding clinicians [9]. Kerrigan et al.'s research highlights that whilst 60%–90% of patients at Royal Darwin Hospital (the main tertiary facility in the NT) are Aboriginal and 60% speak an Aboriginal language, only 17% access an interpreter [10]. These barriers to patient engagement are a significant challenge to effective health promotion and contribute to inequitable rates of kidney transplantation for Aboriginal and Torres Strait Islander people.

The National Indigenous Kidney Transplant Taskforce (NIKTT) was established in 2019 to improve access to and outcomes of kidney transplantation for Aboriginal and Torres Strait Islander people in Australia, and this programme supported several consumer engagement activities, including mentoring projects [11]. The concept of patient mentors, also known as navigators or preceptors, was originally developed in the context of cancer treatment, but has been expanded to other health fields including kidney transplantation where it has been shown to reduce barriers in access to care, address health inequalities and improve health outcomes [12].

Internationally, research has shown that mentoring is an effective strategy for improving kidney health outcomes, including enhancing consumer knowledge, self-efficacy and leading to an increase in transplant rates [13]. A randomised control trial in the United States (US) found that consumers who were supported by mentors completed more than twice as many steps in the kidney transplant work-up process than those in the control group, which was consistent across race and gender subgroups [14]. In this study, the mentors were able to fill a void in the transplant pathway, offer patients support and provide additional benefits to dialysis and nephrology care. The mentors worked closely with pre-transplant nurse coordinators and social workers, and the programme resulted in increased completion of the steps in the transplant process [12].

In Australia, mentors have been shown to address gaps in chronic disease care around health literacy, communication, psychosocial support and coordination across multiple health services [15]. Projects like Aboriginal Kidney Care Together Improving Outcomes Now (AKction) in South Australia highlight that Aboriginal people with lived experience of CKD want to inform health service delivery and planning [16]. In the NT, mentors have been recommended as a strategy to improve the continuity of care for people with kidney disease and address barriers to transplant waitlisting for Aboriginal people [8, 9]. Whilst evidence suggests that mentors can play an important role in the transplant journey and can impact on health outcomes, the role of Aboriginal mentors has not been clearly described in the literature and there is minimal evaluation of current mentor projects.

This article is centred on the following research question: 'What is the role of Aboriginal kidney health mentors and what factors enable or constrain their influence on patient journeys to kidney transplantation'? With funding from NIKTT, Panuku (the Top End arm of Aboriginal Community Controlled Health Service Purple House) implemented a 'Hunting Kidney Transplant' project in the NT to develop the role and status of Aboriginal kidney health mentors. Through a qualitative evaluation of the Hunting Kidney Transplant project, this article contributes to the evidence base around the holistic and multi-dimensional role of mentors, the visible and invisible work they perform and the importance of a Right Way Working approach (Figure 1). Given the health inequalities faced by Aboriginal and Torres Strait Islander people and the devastating impacts of CKD, evidence-based strategies are needed to enhance health promotion, cultural safety in health systems and ultimately improve health outcomes.

2 | Methods

2.1 | Positionality Statement

As co-researchers and co-authors, Aboriginal kidney health mentors (DC, LR, PH, NW, CA, SB) have led the knowledge production process and shared their lived experiences and insights through their role as mentors. This article is underpinned by ongoing, collaborative partnerships between the Aboriginal mentors, researchers (SP and GG) at Menzies School of Health Research and staff at Purple House (HH and MM). Throughout the research process, the co-authors have foregrounded Aboriginal leadership, governance and engagement. Co-authors SP, GG, HH and MM are non-Indigenous and recognise their privileged positionalities and are grateful to learn from and work alongside the Aboriginal kidney health mentors.

2.2 | Methodological Approach

Following calls for First Nations approaches to monitoring and evaluation [17] and reflecting the Hunting Kidney Transplant model (Figure 1), this qualitative evaluation foregrounds

Consumer Voice	Knowledge	Health Service	Purple House	Mentors	Transplant
Advocacy	Culture	Primary Health Care –	Directors	Translate	Patient - Culture
RAAC	Language	ACCHO	Community	Guide	Family
CARV	Lived Experience	Hospital	Two Way working	Link	Community
IRG – NIKTT	Education	Renal Service	Support	Community	
	Research	Transplant Service		Trust	

FIGURE 1 | Hunting Kidney Transplant model and Right Way Working approach.

Aboriginal ways of being and knowing and values lived experience and expertise [18]. In line with Aboriginal worldviews, this evaluation centred on the relationships that were facilitated and maintained through this project, including the relationships between the mentors, consumers, families, community, health services and other organisations. The evaluation approach considers the historical, policy and social landscape of Aboriginal peoples' lives as central to assessing health programmes [19]. In general, health promotion programmes for Aboriginal and Torres Strait Islander people have not been adequately evaluated and there is a lack of information about health promotion action areas like fostering supportive environments and improving cultural safety in health services [20].

The methodology for this article involved 'tracing the hunt' – following the footsteps as patients and mentors navigate across Country and reflecting on their roles and the path taken. 'Tracing the hunt' took place from March to November 2022. Rather than measuring discrete outcomes, a process evaluation examined how the Hunting Kidney Transplant project was implemented and the factors that enabled or constrained the effectiveness of the implementation.

2.3 | Setting and Participants

Evaluation activities took place on Larrakia Country in Garramilla (Darwin) and on Central Arrernte Country in Mparntwe (Alice Springs). Purposive sampling was followed to engage and build relationships with the Aboriginal kidney health mentors and renal staff involved in the Hunting Kidney Transplant project. As this evaluation was focused on understanding the role of the mentors and assessing the implementation of the project, the Aboriginal kidney health mentors and Purple Health staff were the main participants, and co-authors, in the research. Due to the scope and timeframe of the evaluation, people who received mentoring were not included as participants, but this would be a valuable area of future research.

2.4 | Data Collection and Analysis Methods

Six in-depth interviews were undertaken with the Aboriginal kidney health mentors, Purple House staff and NT Department of Health staff. Focus group discussions were used to triangulate and validate information and unpack emerging themes. Participant observation was also used to understand the breadth of activities undertaken by the mentors and document how they communicate and engage with consumer groups and stakeholders. This included observing the mentors present about their work at consumer group meetings and conferences in Alice Springs and Darwin.

Interview transcripts and notes from focus group discussions and participant observation were coded through an inductive lens, identifying themes from the data. Emerging themes were collaboratively discussed and synthesised with the Aboriginal kidney health mentors as co-researchers and key knowledge holders. To capture the connections traced during the 'hunt', Graph Commons software was used to map the relationships between mentors and other stakeholders (see Figure 2).

3 | Results

Within the Hunting Kidney Transplant project, the mentor role has focused on: introducing people with kidney disease to the transplant pathway and clinical teams; building confidence and

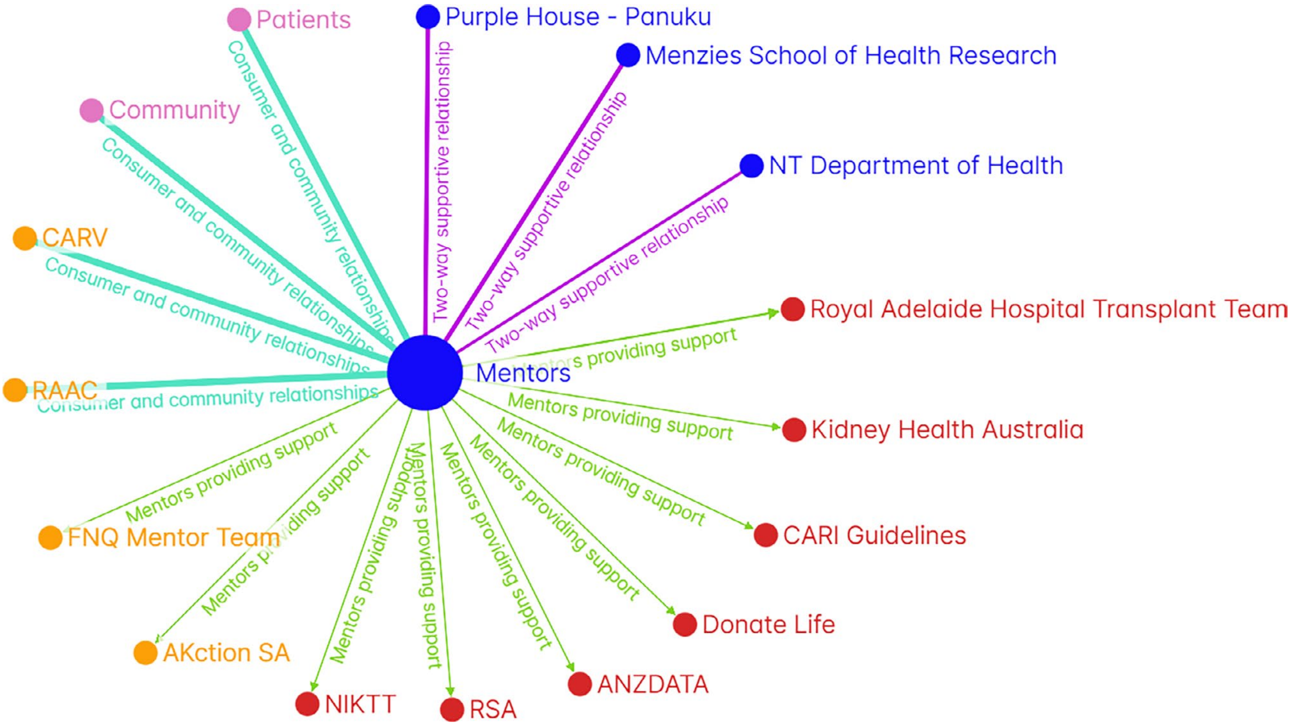

FIGURE 2 | Map of relationships between kidney health mentors and other actors.

trust in the process; sharing information and health promotion; providing emotional support; and empowering patients with knowledge. Since starting their own renal journeys, the mentors have been providing informal and formal support to people at different stages of diagnosis and treatment. Senior mentors DC and LR have shared and developed ways of working with PH and NW, and are teaching more recent mentors CA and SB. The mentor team are supported by Purple House through sustainable paid employment and potential mentors are identified based on their lived experience of kidney disease, transplantation and an aptitude to engage and support others on their journey. Mentors are connected with people based on kinship connections, language, region, lived experience, with considerations given to gender and age.

3.1 | Holistic Role

This evaluation highlighted that whilst the Hunting Kidney Transplant project was focused on transplantation, the mentor role extends beyond this and encompasses a multiplicity of aspects related to kidney health and health promotion. The mentors provide support to people with CKD and ESKD and share their own experiences of different treatment modalities, including dialysis and self-care. As one mentor stated, 'It's all about dialysis to transplant, they [patients] want to know how to do that'. Although transplant may be the ultimate goal of the 'hunt', it is important to understand the holistic nature of the mentor role and how it extends across the renal journey, and beyond. For instance, the mentors provide informal guidance around mental health, housing, Centrelink and other services that can support people with kidney disease. As a clinician expressed, 'You need all these parts to make this transplant successful, so this holistic feel for what someone requires to actually have a good journey for transplant'.

This also speaks to the role mentors play in health promotion, where they share their own experiences around lifestyle and diet and changes across the renal journey. For example, as people on dialysis need to restrict their fluid intake, the mentors would describe their experiences of kidney transplantation and needing to drink more fluids. This holistic understanding of the experiences of dialysis, work up and kidney transplantation enables the mentors to support people at different stages along, an often non-linear, pathway to transplant.

3.2 | Multi-Directional Role

In addition to being holistic, the mentor role is multi-directional and includes building and maintaining relationships with consumers, families, communities, clinicians and other stakeholders. During the 'hunt', the mentors are 'talking about transplant, [saying] you got to go see the doctor [making] the connection with their own GP and community health [service]'. Across the interviews and focus group discussions, the relationship between the mentors and people with kidney disease was consistently referred to as the most important part of their work. Engagement and health promotion with families and communities was also a significant part of their role. Further, the mentors noted, 'It's not only the patients, it's the doctors and nurses. We are teaching some of the doctors and the nurses as well'. Through their lived experience and long-term engagement with health services, the mentors are regularly called on to inform cultural safety in health services.

As illustrated in Figure 2, the mentors have a range of relationships with varied actors, both two-way supportive relationships with key stakeholders (Purple House, Menzies School of Health Research and NT Health) and one-way relationships where the mentors are providing support to other stakeholders. The weighted lines in Figure 2 show the strength of relationships and highlight the importance of mentor connections with patients, communities and consumer groups like the Renal Advocacy and Advisory Committee (RAAC) and the Central Australia Renal Voice (CARV). The 'hunt' for kidney transplantation takes the mentors in a number of directions and their role is to support consumers, families, communities, health services and other stakeholders as they work together on the transplant journey.

3.3 | Visible and Invisible Roles

The evaluation revealed that the mentors undertake both visible and invisible work in their role. They conduct formal mentoring with people who have kidney disease – including helping them navigate the transplant pathway, medication and lifestyle decisions – and attending sessions when the Royal Adelaide Hospital Transplant Team come to Darwin. In addition, they perform extensive work that is less visible, including providing advice at family gatherings, community meetings, consumer group meetings and outpatient waiting rooms. As they described, 'Whenever we are in the community, someone will ask [about transplants], they know we have been through the journey. Family members, heading for dialysis. And if we see someone on dialysis, it just comes naturally for us and if they're having any kind of trouble and they're mentioning it, of course we will just start talking and give them advice'. A Panuku – Purple House team member described the invisible work as including phone calls that happen outside work hours and ad hoc support the mentors provide to consumers and communities. Both the visible and invisible parts of the mentor role are central to supporting patients along the renal journey. The health promotion work that may be less visible to mainstream health services is a crucial part of the mentor role and how they can influence transplant journeys.

3.4 | Right Way Working

A key part of the mentor role is their ability to engage with Aboriginal people and communities in the 'Right Way', including building trust, respect and taking time in the process. This approach is grounded in the mentors' culture, lived experience of the renal and transplant journey and their ability to share stories of this experience to support others. 'That's what we do, that's why we're here now, so we can talk to the patients, we have the experience and have the upper hand in that area'. The mentors emphasise that everyone is on their own journey, and they do not put any pressure on people to make certain decisions. Time is important for working in the Right Way, 'because people want to do their own thing on their own time' and 'it's slow work, just check back on them, don't push it. It's like fishing'. Renal staff highlighted that this is a valuable skillset: 'We [non-Indigenous health workers] can't ever do that, we don't have these skills, but for us to bridge the cultural gap it is essential to get our patients to transplant'. Trust, respect and taking time are therefore key elements for culturally safe and effective health promotion for Aboriginal and Torres Strait Islander people with kidney disease.

3.5 | Enablers

3.5.1 | Purple House Ongoing Support

The ongoing support from Purple House is a major enabler of the Hunting Kidney Transplant project and the mentors' continuing work. Irrespective of project funding, Purple House are committed to supporting the mentors in their role. The Panuku team provide considerable support, including coordinating and organising meetings and travel, connecting the mentors to patients, providing consistent hours and income, ensuring their workload is manageable and offering emotional support. The Panuku team recognise, 'Whoever is in that support space around the mentors needs to be really sensitive to supporting without pushing; not putting that expectation around performance or agenda and allowing if people just need to step away out of that space and [not] work for a period of time'. This long-term relationship and support are central to the role of the mentors.

3.5.2 | Kinship and Community Connections

The mentors have strong connections to consumers and communities and are able to find ways to relate to different people, either through kinship, language or shared experiences of the renal journey. One mentor noted, 'I just want to just share my things to them, and they can share their things to me. Get to know them, you know from different places, and just tell them about having a transplant'. The mentors have provided guidance and support to other mentoring programmes, for example the Aboriginal Kidney Care Together Improving Outcomes Now (AKction) [16] group in South Australia and groups in Far North Queensland. Connections to Country are also a source of strength. Relationality is a key enabler of the way the mentors work and the influence they can have on a person's renal journey.

3.6 | Barriers

3.6.1 | COVID-19

The COVID-19 pandemic and associated impacts on the health system have been a barrier for the implementation of the Hunting Kidney Transplant project. Due to restrictions on visitors to the Renal Units, the mentors were not able to visit, but did continue mentoring from Purple House's Panuku office. COVID-19 made virtual communication easier, and the mentors have continued to meet with patients and other groups through video calls. The pandemic also meant several clinics and visits from the Royal Adelaide Hospital Transplant Team were cancelled. The pressure and competing priorities of clinicians has limited regular cross-organisational meetings, communication and in-person engagement with clinicians. The mentors expressed, '[We are] not really making [connection with health service] … because of COVID, it sort of slowed down. They are down staff, they [have] got all the staff leaving'. COVID-19 impacted on the implementation and evaluation of the Hunting Kidney Transplant project, but this research has identified key elements of the mentor role and ways of working.

3.6.2 | Institutional Racism

Another barrier to the mentor work is institutional racism within the mainstream health system, which is dominated by a Western biomedical model that often marginalises Aboriginal worldviews on health and wellbeing [21]. The mentors are acutely aware of this, 'Sometimes they [clinicians] don't mean to but it's racism, you know that mild racism. … When you're sick, that's the last thing you want to deal with'. Institutional racism – for example, structural barriers to accessing interpreters, lack of recognition of the role of family members in decision making, lack of understanding about the time needed to make decisions about care – is a barrier to the way the mentors engage in the mainstream health system [22]. To address institutional racism, the mentors also provide training and education to clinicians about Right Way Working. It is important to embed Aboriginal mentors with lived experience of chronic conditions into the health system to enhance cultural safety.

4 | Discussion

Other research has indicated that mentors need to be embedded in the health system to optimise the use of resources to benefit patient care, for example information sharing and care pathways [12]. Although ongoing support from Purple House has been a key enabler of the work of the mentors, their positionality in the Aboriginal Community Controlled Health Service sector has influenced the impact and scope of their work. The dynamics between government and non-government health services in the NT and limited information and resource sharing also impact on when, where and how the mentors are engaged in the patient journey. Throughout the evaluation, the mentors expressed that they want to be more engaged in the government health service, including in transplant clinics and family meetings with consumers and clinicians to help provide guidance about decision making – 'What we would like to see is the health system involving us in the [mentor] positions'. A clinician stated, 'There's a willingness from all sides of the team to have mentors in the transplant process and I think it comes down to government and funding and then getting those roles embedded into the workplace'. Although COVID-19 was a barrier to the mentors' activities during the Hunting Kidney Transplant project, further work is needed to integrate the role of the mentors into the government health service.

Funding from the NIKTT has supported the Hunting Kidney Transplant project, but further funding is required to develop, embed and evaluate the mentor role within the health system. The mentor role is distinct from existing Aboriginal Health

Practitioner and Indigenous Liaison Officer positions as it is grounded in lived experience and focused on navigating patient journeys, rather than clinical or administrative service provision. Embedding mentors within the health system requires extensive effort to address barriers, like institutional racism, and ensure a culturally safe workplace. This fits within the recently launched First Nations Australia Guidelines for culturally safe clinical care for kidney disease, which emphasised addressing institutional racism, promoting cultural safety training, and acknowledging the involvement of community throughout the kidney journey [23].

Whilst the mentors emphasise the importance of having both men and women in the role, there has been challenges in engaging women as mentors, including their caring responsibilities and roles in community. For the mentors to work in the 'Right Way' and respect Aboriginal protocols and customs, gender rules must be followed, and greater representation is needed across ages and regions. During this project, five mentor roles were established in the Top End region and one role in Central Australia, but the mentors are keen to train others in this role to expand their reach.

5 | Conclusions

By tracing 'the hunt' and learning how the mentors connect with consumers, clinicians and other stakeholders, this article has highlighted the holistic and multi-directional role of Aboriginal kidney health mentors. Whilst this project was centred on kidney transplantation, the mentors have lived experience across the renal journey and their work extends to people with CKD and receiving different dialysis modalities. Drawing attention to both the visible and invisible work that the mentors perform is central to understanding how their role can improve health outcomes for Aboriginal and Torres Strait Islander people with kidney disease and the importance of the Right Way Working approach. This evaluation has identified key components of the role of Aboriginal kidney health mentors and ways of working, as well as enablers and barriers that should be considered. Further support and funding are needed to develop, evaluate, and embed the mentor role into policy and practice to improve patient journeys, health promotion, transplant rates and ultimately outcomes.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Research data are not shared.

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