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Consumer perspectives of quality care: Exploring patient journeys from remote primary healthcare clinics to Alice Springs Hospital

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ABSTRACT

Problem or background: Residents of Australia's remote regions have lower life expectancies and poorer health outcomes than other Australians. Access to hospital and specialist care frequently requires transport via road or air and time spent away from family and community.
Question, hypothesis or aim: To explore consumer perspectives of the journey from remote communities to regional health services and identify areas for improvement.
Methods: Individual interviews (n = 16) and yarning circles were used to collect and interpret stories of patient's journeys.
Findings: Travel for medical care was common and often required multiple journeys. Complex social and financial barriers to accessing care included costs associated with travel, food, and accommodation for patients and their families, a lack of understanding of the process and requirements of retrieval, difficulty arranging own road transport, and lack of availability of services within the community. These barriers extend to difficulties in attending follow-up outpatient appointments and return to the community after a journey to the hospital.
Discussion: Educational resources may also be used to describe the retrieval process to remote community members to demystify acute health care in Central Australia but also to express the health service commitment to quality improvement through consumer voice. These resources may be used to orientate new health service employees to patient experiences and perspectives so that these can be incorporated into care planning to enhance cross-cultural understanding.
Conclusion: Travel to access healthcare is an essential component of health services for remote communities. Targeted education for residents on travel expectations and education for staff may significantly reduce barriers to healthcare access.

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Summary of relevance

Problem or Issue

The perspectives of remote-living people on their transport journeys to hospital are not well understood.

What is already known

Residents of Australia's remote communities have significant health needs that are not provided within their community settings. Travel for health care is a barrier to accessing services.

What this paper adds

Education and preparation for patient journeys, alongside increased financial and personal support, can enhance the experience and acceptability of travel for healthcare purposes. Culturally, safe care throughout the whole journey from home to hospital via road or air, and back again, is essential to improving acceptability and improved health outcomes from the consumer perspective.

1. Introduction

Globally, rural and remote populations experience limited access to healthcare services with associated poorer health outcomes. Primary healthcare services in these regions are focused on public health, primary care, and management of chronic disease but must also deal with acute and critical illness requiring referral and transportation to higher-level care (World Health Organisation & United Nations Children's Fund, 2018).

Central Australian remote populations are small and geographically isolated, have high proportions of Aboriginal people and residents experience poorer health outcomes (Australian Institute of Health and Welfare, 2022). The term 'Aboriginal' and 'First Nations' is used throughout this paper as preferred by the Central Australian consumers in this study. We respectfully acknowledge that Torres Strait Islander people are also First Nations people in Australia. Clinics are most frequently nurse-only posts with a high variability of service, including Aboriginal health practitioners (AHPs), visiting general practitioners, and allied health and telehealth. Health services are provided through either Government or Aboriginal Controlled Health Services.

The Central Australia (CA) region covers a geographic area of 873,000 km^2 with a population of over 46,000 people, of which 44% identify as Aboriginal for whom English is often the third or fourth language. There are two regional hospitals, Alice Springs (ASH) is the major acute hospital and Tennant Creek Hospital. About 60% of the Central Australian population lives in Alice Springs. The remaining 15,000 residents are distributed across over 50 remote Aboriginal communities, outstations, and cattle stations with populations ranging from under 50 to around 1000. Telecommunication and transport options are severely limited.

When patients require a level of care beyond what is available in their community, they are transferred by road or air to ASH. Onward transport to a tertiary facility (Darwin or Adelaide, both 1500 kms from Alice Springs) may be required. The Medical Retrieval and Consultation Centre (MRACC) delivers a medical retrieval service for acutely unwell patients, inter-hospital transfers, and repatriation back to their community for Central Australians (Mathew et al., 2022). MRACC is staffed by critical care-trained retrieval specialists and provides a single point of contact for emergency consultations for remote healthcare staff (Shahtahmasebi, Johnson, & Shahtahmasebi, 2020).

A recent meta-analysis highlighted the importance of understanding Aboriginal and Torres Strait Islander experiences of healthcare delivery (Jones, Heslop, & Harrison, 2020). Of relevance to this study, they found that trust and interactions with the health system were critical factors in timely access to health care, particularly for rural and remote residents (Jones et al., 2020). Barriers to healthcare access were feelings of disempowerment and shame, language barriers, racism, and negative past experiences of hospitalisation. The positive aspects were a welcoming environment, respectful, culturally competent staff, and a community feel to the health services (Jones et al., 2020).

Barriers and facilitators to retrieval for remote residents of CA are not currently known and there is a need to explore the patient's experiences of the pre-hospital primary healthcare service and return to the community in order to provide a comprehensive account of the patient's journey (Kelly et al., 2015b).

2. Research aims and objectives

This study aimed to understand the consumer experience of retrieval from a remote primary healthcare service to ASH and beyond.

The main objectives were:

- To identify barriers and facilitators to a positive retrieval experience from the consumers' perspective
- To identify indicators of culturally appropriate quality care from a consumer perspective
- To collect stories of retrieval and the acute healthcare experience that can be used for community and health professional education

3. Significance

This research is of interest to both residents of remote communities and health industry partners, including health departments and community-controlled medical services, as it provides important information on the quality and cultural safety of health service provision.

The perspectives of healthcare consumers are essential in empowering people and providing access to health services where they feel safe (Pons-Vigués et al., 2017).

4. Participants, ethics and methods

We followed the 'Managing two worlds together' (MTWT) framework (Kelly et al., 2015a) to collect people's transfer stories. This framework mapping was "…developed in collaboration with Aboriginal patients, their families and carers, staff in city and rural and remote hospitals and health services" (Kelly et al., 2015a p.1) and validated in a contextually similar region.

Data were collected through narrative accounts from patients where the stories being told relayed the path taken and factors that affected access and quality of care were clearly identified. Data collection and analysis were facilitated by an Aboriginal researcher (who is also an AHP) from CA (EL — first author of this paper) inline with cultural safety and Indigenous research principles and ethics (National Health and Medical Research Council, 2007, 2018). The other members of the research team are nurses (AG, RS and KM) and the former director of medical retrieval services at ASH (RJ).

The patient journey included the hours and days before transfer from their community, through the transfer process (which may include transfer to another service such as Adelaide and return to Alice Springs) and concluding with the return to their home community.

4.1. Data collection (Yarning)

Yarning has been used as a method of sharing and developing knowledge among First Nations Australians for many generations (Dean, 2010). First Nations people in Australia generally view yarning as a 'conversational process' or a cultural version of conversation (Walker, Fredericks, Mills, & Anderson, 2014). As a data collection method, yarning involves the sharing of stories but goes beyond this to establish relationality between participants and researchers (Walker, Stomski, Price, & Jackson-Barrett, 2014). Yarning therefore functions as both a data collection method and a way of communicating

accountability between researcher and participant, vital to the objectives of this research project.

Direct questioning was limited to prompting questions, orientating the conversation toward the collection of stories about the journey and its impacts. During conversation, a mutual and contemporaneous analysis of concepts can occur when the researcher assumes the mantle of learner and participants can ensure their stories are heard correctly through a method known as Dadirri or 'deep listening' (Bessarab & Ng'Andu, 2010).

5. Data analysis (narrative enquiry)

The rigour in yarning as a methodology is allowing the yarn or story to flow leaving the researcher to pick up the segments that relate to the research (Bessarab & Ng'Andu, 2010). Narrative enquiry methods were applied to analyse each yarn (Emden, 1998), developing core stories from narrations by following eight steps: read the interview many times over a few weeks, delete questions, delete words that do not add to the main points, re-read, repeat the previous two steps until all main points are illuminated, identify themes, and move themes around to create the core story or a series of stories (Emden, 1998). We used Microsoft Word to assist with data management and coding. The core story is often a lot shorter in length. Member-checking the stories and interpretation was guided by our Aboriginal co-investigator and focus groups of Aboriginal health workers. The non-Indigenous researchers maintained a reflective journal, noting memos during the analysis process to aid in reflexivity.

6. Setting and sample

This project documented the retrieval stories of residents from Central Australian remote communities. Although a small number, these participant experiences sought to be representative of generational, gender, and common medical conditions (e.g., obstetrics, renal, cardiac, and trauma) experienced by Central Australians from diverse communities. However, we note that every retrieval experience is unique, and the pool of potential participants is small. Therefore, a pragmatic approach was adopted based on the availability of participants.

Participants were ineligible for inclusion if they were

- Medically or psychologically unstable (including under the influence of alcohol or drugs (including prescribed medications e.g., opiates)) that impair cognition
- Cognitively or intellectually impaired or under the age of 18
- Not proficient in English or no availability of interpreter for consent process

7. Recruitment

Potential participants who were currently inpatients at ASH, were identified by MRACC and communicated to the researcher on-site who applied the inclusion/exclusion criteria. Informed consent was obtained via provision of a Participant Information Sheet and Consent Form accompanied by a verbal explanation of the study by the Aboriginal researcher. Participants were given the opportunity to discuss their involvement with family members and to ask questions.

8. Interviews

Interviews (up to 60 min) were conducted in the patients' hospital room, audio-recorded in English and Aboriginal language, transcribed by a research assistant and translated by the Aboriginal researcher to adequately represent their meanings and ensure "terms and concepts are drawn from the words of the participants" experiences and perspectives (Stringer, 2013) the verbatim principle were used. Cultural limitations and expectations were managed between the Aboriginal researcher and the participant. Transcriptions were reviewed by the Aboriginal co-investigator to ensure accuracy and clarify words or phrases that were not spoken in English.

9. Focus groups (yarning circles)

The research team identified a need for additional interpretation of findings because we were unable to report back the findings or 'member check' the data with participants because they had returned to their communities and were unable to be located. Therefore, we sought additional information from relevant Aboriginal staff, which increased the validity of the findings and reduced potential for bias towards a non-Indigenous viewpoint. Yarning circles describe a method of group conversation, similar to focus groups (Eady & Keen, 2021), which were led by the Aboriginal researcher for this purpose.

Aboriginal Liaison Officers and Remote Community Engagement Officers (n = 5) were identified by the Aboriginal Partnership and Strategy Unit lead and Remote Primary Healthcare Manager, both based at ASH. The yarning circle met three times. Initially to establish a relationship between the research team and participants and discuss the project aims and participation expectations. The second meeting discussed interpretation of the results. A third focus group was convened at the request of the participants to further the discussion.

10. Ethical considerations

Special consideration of National Statement requirements for Aboriginal and Torre Strait Islander and other vulnerable people has been incorporated into this project. Ethics approval was granted by the Central Australian Human Research Ethics committee (approval number 21-3985) and the Edith Cowan University Human Research Ethics committee (approval number 2021-02491).

Anonymity has been ensured throughout by removing, during transcription the identity of the participant, their community or any other person named in the interview. Individual participants were offered a $25 supermarket gift card in recognition of their time and expertise. Yarning circle participants were provided with lunch.

11. Participants

11.1. Individual yarns

About 16 Aboriginal participants (6 male and 10 female) were interviewed: 8 were over 50, 5 were 18–49 years old and 3 were children whose story was told by parents. Participants travelled from 11 different communities. Clinical reasons for retrieval included cardiac (*n = 4*), sepsis (*n = 2*), respiratory (*n = 2*), stroke (*n = 2*), childbirth (*n = 2*), complications of chronic illness (*n = 3*), and gastroenteritis (n = 1).

12. Yarning circles

Five Aboriginal liaison officers (2M and 3F), with hospital experience ranging from 1 year to more than 10 years, participated in the Yarning circles. Whilst our intent was to explore participant journeys from the local clinic, continuing through retrieval to hospital admission and then from discharge back to the community, Yarning circle members also stated that journeys included the repatriation of a deceased person back to their community for burial that can be a complicated and distressing experience.

13. Findings

To reflect the nature of these journeys, the data are presented as themes relating to each stage of the journey. One example of a journey yarn, is included in Appendix A.

13.1. Before leaving the community

Remote primary healthcare clinics often serve vast geographical areas, so travelling from home to the clinic is often a journey in itself:

> *I was visiting friends in a remote community, and I got chest pains. A lady drove me to the nearest clinic at Canteen Creek. I've never been through these roads before… I felt like, shaky bit shaky, bumpy road (11)*

Travel on unsealed and isolated roads with many hazards, including wildlife and water crossings, is particularly difficult at night. Fuel availability, patchy mobile telecommunication coverage, and poor vehicle maintenance are frequent concerns. Patients described fearing getting a flat tyre or being pulled over by the police for traffic infringements such as lack of registration.

Some participants were concerned about the availability of nursing staff at the clinic after hours "*They ask the clinic for help, …. Nobody will open the door. they ring them. Nothing. No luck. They have to wait until next day when the clinic opens." (YC1)* and the lack of alternative service providers, for example, "*Before he got unwell they were asking for a dressing in the community clinic but it wasn't given so they used a rag to cover his wound.Sometimes they try and stop the clinic vehicle and the car doesn't stop it just keeps going." (1).*

Further barriers or worries focused on the lack of resources or highly trained staff. Two participants described staff as being 'panicky' (7) and 'shocked' at their presentation:

> *We went to the clinic quickly and they were shocked.they said, you're having a baby…I was shocked…[but] everything's alright…normal. My family brought me my clothes and key card. It wasn't scary. But the clinic staff were in a panic saying, "the baby's coming!'* (20)

One participant expressed frustration that she was required to be transported at night against her request to wait until the next day:

> *It was just, a boil… my blood pressure was high, sugar was high, and oxygen. I don't know…I said to a nurse I wanted to go the next day, Tuesday, because I didn't want to fly at night. And they was telling me that "…you'd end up to ICU and you might die…" I ain't gonna die when I'm talking to you [today]! (19)*

However, another described their time at the clinic while waiting for the retrieval service as positive: "*I felt safe… at the clinic … they helped and treated him with respect for [they weren't cheeky]"*

Patients often did not fully understand why they needed to be transported, how long they should expect to be away or what they might need during their time in hospital. Patients often left the community without adequate clothing, money, or ability to communicate with family left at home. Some patients were distressed at the prospect of leaving children behind and there was fear that retrieval may be the last time that person sees Country/community.

13.2. On-route

> Overall, participants in this study expressed satisfaction with their retrieval experience, "On the plane [they] made sure you're comfortable. Are you OK? Speak up, if any pain. Just try to relax, but they kept waking me [up] … it was good… they told us [where] we were going to go…." (2)

Some patients were transported via road depending on the distance to be travelled and the patient condition. However, discomfort related to the cramped nature of the aeroplane and need for restraint on stretchers was also a common complaint:

> *I had to organise some stuff … On the plane the flight nurse didn't really explain what she was doing. It was just Me and baby… the safety belts where they put it around tight (18)*

Most patients travelled alone without a family escort due to weight restrictions and the possibility of being re-routed to pick up another patient. In some stories, participants described having time to sort out the essentials and others were put on the plane without any belongings or access to money, for example, "*Transport was too quick, only one set of clothes that I'm wearing - I came alone, basic card, key card at home everything at home" (17)*

Patients expressed distress at having to travel alone, stating that having family with them was important for well-being. Families left behind generally made their own way to the hospital, which took time due to transport and accommodation costs. Anxiety about travelling in the plane or at night was evident in the stories shared, "*It's really hard to get them get them on the plane. They think they might crash and all that. Especially old people. Sometimes they need someone there to comfort them and explain" (7).*

13.3. Hospital admission

The stories told often focused on the experience of staying at ASH. The ALOs (Aboriginal Liaison Officer) provide an important service to Aboriginal patients in welcoming and supporting them during their hospital stay, providing an essential link between hospital services, systems and staff, and First Nations people by facilitating access to services and aiding communication with families and inpatients.

> The ALO's *I know most of them. We get on good with them. They're a good help. If there's a problem with the nurses here or something we report to them, so they make sure … the problem [doesn't] get bigger (4)*

Participants in this study often expressed satisfaction with the care provided:

> *I feel really grateful to be here. I've experienced other hospitals, what it's like and I reckon it's the best hospital… as I see it, there's a lot of good staff and nurses are friendly, and they comfort you when you come from that distance, they are there to comfort you (7).*

Language barriers increased the difficulties with communication, for example,

> *They* [doctors] *checked baby. They spoke to mother and then I [Grandmother] said mum [baby's mum] doesn't speak English … the doctors said we are going to Adelaide and we are taking the baby. … the doctor said there is a hole in the heart …. my daughter asked me to explain everything as she didn't know what was happening (16)*

The example in Appendix A further highlights the importance of clear communication between health staff and patients and the importance of respecting the patients' 'space'. Other participants described similar feelings of discomfort when they were woken very early in the morning by staff delivering breakfast without expectation or explanation of who they were or their role.

The ALOs explained the importance of effective communication and the use of many languages across the Central Desert. Communication was a major barrier and the ALOs discussed the need for health workers in the community and hospital setting to learn simple phrases from many language groups, so everyone feels equally welcome. Further, ALOs supported the ability for Aboriginal people to be able to discuss matters privately in a language that non-Indigenous health workers did not understand, which gave them increased empowerment in health decision-making.

13.3.1. Bush medicine and traditional ways

Several participants described using 'Bush medicine', believing in spiritual causes of their ailments or consulting with traditional healers known as Ngangkari during their stay in hospital. These patients suggested that Ngangkari needed to be operating full time at the hospital, paid for by the hospital and their recommendations incorporated into their care. Cost for community members was identified as a barrier to all patients in need receiving help from the Ngangkari. For example,

> *We need to see Ngangkari visiting more often…. Work alongside the hospital with the doctors and the staff here. [Ngangkari] they want a big amount of money. I'm looking at chucking 500 dollars just to make him happy… That's how it works in Aboriginal communities. (4)*

Although ASH did not have Ngangkari in the hospital on a permanent basis, the ALOs did describe calling upon them when needed such as, when a patient dies in the hospital to capture the spirits and set them free. The ALOs also discussed stories where patients or their escorts died whilst they were away from country/community either because of the health condition they were transferred for or as unrelated incidents.

> *They're not gonna get back here. Nobody's gonna pay for you. … Yeah. So hard. If you die in Adelaide…Yeah, you gotta [ask family] paying …Then the body comes back… and ohh that poor husband. Poor thing. Just to bring it back home…They put his body in the back of the bus. (YC2)*

13.4. Discharge and return to community (including follow-up appointments)

On discharge, patients were often placed in hostels so that they could stay close for outpatient follow-up. This situation generated vigorous discussion between the ALOs as one of the hostels was lacking in basic living standards. Food was not supplied, and many patients did not have the money, so often, ALOs from the hospital would provide some basic food if they were able to. Many patients did go back to the community on bus in preference to staying at the hostel.

Discharge against medical advice or patients not attending outpatient appointments was a problem identified by the ALOs in relation to hospital discharge.

> *He was meant to attend an outpatient physio appointment, but he didn't have any money. [ALO] advised him that the bush bus should be able to pick him up and one-night accommodation then drop him back home – Paid through PATS. He was not advised of this when he left the hospital – ASH gave him one week's medication, but he doesn't have anymore. The nearby clinic has not been in touch (12)*

Staying in town to be close to services and being away from the community for long periods of time placed social and financial obligations on family members:

> *Family have not gone back to the community. They were in Alice Springs for 2–3 months [hostel] and now in Melbourne and bub gets the operation tomorrow. They are staying in a Ronald McDonald house, [but] they have no money or phone credit - no complaints with staff or the hospital (16)*

14. Suggested improvements

Whilst participants in this study seemed satisfied with the care provided by healthcare staff in relation to their physical health needs, social, and cultural care needs were often overlooked. Costs associated with travel, communication difficulties, and lack of consideration of cultural beliefs within the care plan were areas for further improvement. Suggestions from participants for improvement to retrieval processes included:

- Education about entitlements and reimbursements of costs through patient travel assistance services
- Provision of education packs/resources that assist people to know what to take (e.g., identification documents and money) and what to expect
- Information about different travel options such as the 'bush bus'
- Have a timeline for when patients are in hospital, outlining the routine, for example, blood gets taken at 0600, breakfast comes in at 0700, and visiting hours.

15. Discussion

This study aimed to describe the experiences of Aboriginal people living in remote communities who needed to travel to a major centre for health care. We found that travel for medical care was common and often required multiple journeys for themselves or family members in order to access care. Our study identified a range of complex social and financial barriers to accessing care, including costs associated with travel, food, and accommodation for patients and their families; a lack of understanding of the process and requirements of retrieval; difficulty arranging own road transport and lack of availability of services within the community. These barriers extend to difficulties in attending follow-up outpatient appointments and return to the community after a journey to the hospital and are similar to the MTWT study (Kelly et al., 2011), where patients and their carers reported communication difficulties and uncomfortable relationships with staff as significant challenges in their journeys from their remote communities to Adelaide Hospital. Furthermore, financial costs, systemic barriers, lack of interpreters, and other supports along with a lack of care coordination and social/cultural links also impacted negatively on the consumer experience of care (Kelly et al., 2011).

15.1. Health and well-being from an Aboriginal and Torres Strait Islander perspective

We found that access to culturally appropriate caregivers, such as Ngangkari and AHPs, combined with care provided on Country or within the context of family and community, was important to our participants. This finding aligns with Aboriginal and Torres Strait Islander people's broad and holistic view of health, which includes connection to Country/community and family, physical, emotional, social well-being, spiritual, and cultural integrity (Gee, Dudgeon, Schultz, Hart, & Kelly, 2014).

This holistic view may conflict with the process of retrieval that focuses on clinical urgency and resource availability, including local health service capacity, staff clinical skill sets, and fatigue. This biomedical approach may not consider the holistic worldview of First Nation's patients for whom the Aboriginal concept of personhood is a holistic one, existing in the relationship one has with others and the natural or material world (Grieves, 2009). In writing about East Kimberly Indigenous worldviews, McDonald (2006) argued that in the local relational worldview, reciprocity, and moral causation were tied to the causality of both health and ill-health (McDonald, 2006). Health practitioners should not ignore this culturally derived sense of personhood and disease causality when they seek to help individuals and communities become, or stay, well. A difficulty exists however, as Western health practices and health delivery mechanisms have evolved from a juxtaposed concept of individualised personhood where social and spiritual relationships are not always considered relevant (Grieves, 2009).

15.2. Two-way understanding

CA is home to First Nations people with varying familiarity with Western values and processes. For many people, functioning simultaneously within 'white ways' and Aboriginal worldviews is common practice, we suggest that many contemporary First Nations people

'code switch' depending on their cultural context at the time with Western and Indigenous approaches to health not necessarily exclusive or privileged (Chirgwin & Huijser, 2015, p. 344). Actions that increase accessibility to cultural and spiritual services whilst in hospital may result in improved health outcomes. Alongside this, improved communication of what to expect, what to take with you and how to communicate with family whilst hospitalised may enhance family connections and social support and reduce unplanned discharges.

Non-Indigenous health workers in regional hospitals are unlikely to have experienced the challenges and rewards of living in a remote community and therefore their ability to empathise and understand the experiences of remote residents may be a factor in difficulty with cross-cultural communication and provision of culturally safe care. Current cultural safety training should be reviewed to reflect this. Key personnel from the non-Indigenous healthcare team could meet with the ALOs on a weekly basis to discuss concerns and events with ideas and solutions being a collaborative approach, for example, access is often an obstacle, travel, accommodation, paperwork and funding, and together the team can improve coordination of care.

16. Recommendations/implications for practice

16.1. Cultural safety

While literature addresses how cultural safety may be achieved, contemporary practice requires the definition of cultural safety to be made by those who receive services (Best, 2014). Even when healthcare spaces are culturally safe and welcoming, automatic engagement with Indigenous communities is not guaranteed (Howard, Ingram, Liu, Mentha, & Peiris, 2014). People make sophisticated treatment and management decisions based on their socially connected experience in every society. For the remote context, this socially constructed expectation of 'wellbeing' is not often common ground between biomedical health providers and rural communities as it is within mainstream settings.

Davy et al. (2017) and Fogarty, Lovell, et al. (2018) call for the use of cultural evidence alongside scientific evidence to empower communities to set local priorities for health service delivery. This privileging of cultural evidence alongside the western paradigm of research-based practice is ground-breaking. However, when striving for developing a multidisciplinary team, which includes all forms of evidence, health providers may continue to struggle to identify or engage with cultural connections. Davy et al. (2017) suggest the co-location of traditional healers with mainstream health services as a solution. This is a recommendation of this research.

16.2. Development of education interventions to enhance two-way understanding

The importance of two-way understanding between remote-living First Nations communities and urban health services — including those undertaking retrieval services — is an important finding from this study. Therefore, we recommend the development of educational resources as interventions to enhance cross-cultural understanding. The resources may be used to orientate new health service employees to patient experiences and perspectives so that these can be incorporated into care planning. These resources may also be used to describe the retrieval process to remote community members to demystify acute health care in CA but also to express the health service commitment to quality improvement through consumer voice.

16.2.1. A video to co-locate the biomedical and contextual knowledge about retrieval

The ALOs suggested a short video explaining the reasons for delay in the plane arriving, such as that it takes time to prepare the plane or other sicker patients need it first. Understanding the resource limitations and process requirements may increase patient satisfaction and possibly even reduce the number of after-hours calls. An educational video could also describe the social and cultural experiences of the patients being transferred to educate health professionals about those needs. One focus group discussed having a map tracking the plane as a visual method improving transparency between the three different components (community, retrieval, and hospital) of a patient's journey.

16.2.2. Patient transfer passport

Yarning circle participants also suggested that patients being transferred by road or air be provided with a form that includes information and phone numbers for the clinic, the hospital ALOs and patient-assisted transport services. In addition, the form should have room to write the patients' expected transfer destination and duration of time away from the community. Information about accommodation in town, for example, hostel, can be included. A copy could also be given to family members and remains in the patient files at the clinic.

16.3. Study strengths

This study was designed from a strength-based perspective where the voice of Aboriginal participants was privileged, which means that this project *respects* and assists in the *survival and protection* of Indigenous knowledge. The Indigenous research methodology, interpretation and data collection for the study was led by Aboriginal people and the collaboration with non-Indigenous health workers as co-researchers enhanced efforts to reach *equality* in research practice. This approach aims to redress past inequities in research practices. The additional value of this study comes with the future development of the educational intervention and presentation of findings back to communities in the Central Desert region. In this way, this study demonstrates reciprocity and translation of research findings to benefit the participants and their communities.

16.4. Study limitations

The diversity amongst First Nations communities in Australia and the small sample size in this study limit the generalisabiliy of the findings. However, we believe the underlying principles of respectful community engagement with health services enabling this study, may be easily replicated for other First Nations remote communities around the globe.

Although the study was led by Aboriginal people and none of the investigators were involved in the clinical care of any participants or families, it was still carried out in a health setting and the authors acknowledge potential for power imbalance and associated positive reporting bias.

17. Conclusions

This study identified key areas of improvement for retrieval-remote CA to improve First Nations people's experiences, understanding, and health outcomes. Community members identified the need for increased funding and support for accommodation and travel both to improve the maintenance of family connection whilst in hospital, and also timely return to Country/community. The development of educational resources to inform community members and healthcare staff of the experiences of retrieval and return to Country/community, which also improves two-way communication and culturally safe care, should be developed.

Authorship contribution statement

Emslie Lankin: Conceptualization, Data collection, Formal analysis. **Amanda Graf:** Conceptualization, Methodology, Data collection, Formal analysis, Writing – review & editing. **Rebeca Schultz:** Conceptualization, Writing – review & editing. **Richard Johnson:** Conceptualization, Writing – review & editing. **Kylie McCullough:**

Conceptualization, Writing – original draft, Project administration, Funding acquisition, Formal analysis.

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Conflict of interest

Richard Johnson is currently acting as executive director of Medical and Clinical Services of Alice Springs Hospital and was previously the director of the Central Australian Retrieval Service. Rebecca Schultz is the current director of nursing and midwifery, public and primary health care, Central region NT.

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Appendix A. Parent description of a patient journey

I noticed that she had high fever and wheezing. She's got bad asthma. I gave her medication and then ring the clinic. So that's my plan and I took her to the clinic before 5:00 o'clock clinic closing time. Sometimes, they take their time to turn up after hours. That sometimes makes me feel angry. The clinic staff said they were coming to pick her up in the clinic vehicle. Then, the nurses rang the hospital to speak to the doctor. I was worried about her, too. Better than keeping her out there. I was there for about an hour. I was asking them question as well. I was in hospital last week with her. Got discharged Friday and came back on a Monday afternoon. My 20-year-old daughter had to look after my other child.

They drove me to ASH in the Troopy ambulance. It takes about an hour. It's only 80 km on an unsealed road but it's getting bad with the corrugation. At ASH, we went to the triage, then to the kid's outpatient emergency room. I'm used to it being in hospital because my son was diagnosed with leukemia.

The staff were asking me if I had anyone in town I could stay with and I said "no". I do know people, but I wanted to stay here in case she gets sick. My stay at ASH would be better if the cleaning mob didn't just walk in and start cleaning. You're still asleep, you know, they just come in and clean up without saying hello. I feel sort of embarrassed. You know, when you are sleeping, you don't like it if someone goes into your house and cleans up. This is like your home for now.

Last week when we first came in, we were both asleep from staying up all night. We're still asleep and I got a fright because the nurse came and gave medicine to my child. I got a bit angry because she didn't wake me up.

Well, it's alright coming in with the ambulance, but sometimes they don't come on certain days. Sometimes, I just ask my sister, or I call the hospital and ask them to cancel this appointment. If you do find your own vehicle, at least they should supply fuel.

I feel comfortable with the staff but you can tell by their body language, you know. The Aboriginal just say 'morning' and just keep walking. They need to come with us if we need anything or see how we are doing. Like in Women's and Children's Hospital in Adelaide, they do everything. I get bush medicine from one of the ladies who's staying upstairs looking after her niece. I usually make our own at home. If you get Ngangkari yourself, you have to pay them with your own money.

They could support people from remote communities by providing accommodation if you have appointments like 9:00 in the morning. They could also offer spiritual support from a Chaplain, and they need interpreters. Because I hear some people struggling and they don't understand and they use hard words in the hospital.

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