DISABILITY AND REHABILITATION
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RESEARCH ARTICLE

"Well, I may as well go home because I felt no one was listening to me": yarning with aboriginal peoples and communities about stroke recovery and experience. A qualitative study

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ABSTRACT

Purpose: To understand the stroke recovery experience of Aboriginal Peoples living with stroke on Gamilaraay/Gomeroi country in New South Wales, Australia.

Materials and methods: Community participatory action research methods were undertaken incorporating individual and group yarn-ups with Aboriginal Peoples in the community living with stroke and their family. A non-Aboriginal qualitative researcher undertook inductive narrative analysis of the emergent themes in the yarns, with frequent review and input from Aboriginal and non-Aboriginal clinician researchers and the Aboriginal working group.

Results: Yarns were completed with (i) people living with stroke ($n=5$, 60% female), (ii) family and carers of people living with stroke ($n=5$, 80% female) and a (iii) well-established community group ($n=6$, 100% female). The four themes were: (i) The role of family in stroke recovery, (ii) Trusted relationships with people aware of stroke and support options, (iii) Importance of culturally appropriate interactions with health service, and (iv) Disrespect and racism impacts stroke care access.

Conclusions: The role of family, trusted relationships, community connection, cultural safety and respect must be considered in improving the post-stroke quality of life for Aboriginal Peoples on Gamilaraay/Gomeroi country. These learnings can be used as a framework to inform future work with other Australian Aboriginal communities.

*Our research group works with Aboriginal Peoples from Gamilaraay/Gomeroi country located in the North-western Plains of New South Wales Australia. We recognise the diversity of Aboriginal and Torres Strait Islander Peoples from across the many Countries of this place we now call Australia. Recognising this, throughout this text, we have used the preferred term "Aboriginal Peoples".

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IMPLICATIONS FOR REHABILITATION

- A stroke within this Aboriginal community affected both the individual experiencing the stroke and their family and community connections.
- Engaging both an Aboriginal stroke survivor and their family in culturally safe stroke recovery care, which is free from racism and disrespect, will strengthen their ability to self-determine their recovery.
- Connecting Aboriginal stroke survivors with culturally safe rehabilitation and social services prior to discharge home, may improve their participation in rehabilitation activities and strengthen their long-term health, function and well-being after stroke.

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Introduction

Stroke is the second leading cause of death globally after ischaemic heart disease [1]. In Australia, it is the leading cause of disability and the third leading cause of death [2]. Aboriginal and Torres Strait Islander People of Australia (hereafter respectfully referred to as Aboriginal Peoples) make up about 3.3% of the total population [3]. Data on stroke among Aboriginal Peoples is limited, even more so limited is the research related to the experiences of Aboriginal People and their stories of stroke recovery [4]. Acknowledging the social, cultural, political, and historical contexts that continue to impact Aboriginal People's health and wellbeing as a result of colonisation in Australia [5], we choose not to highlight the alarming and often inaccurate stroke statistics [6] for Aboriginal Peoples of Australia or contribute to these statistics that problematise Aboriginal People and communities [7]. Instead, by not highlighting the statistics, we challenge how we write narratives of our research to privilege the voices of stroke survivors and their families, whilst recognising the need to do research with and by Aboriginal Peoples, opposed to on and for.

After experiencing a stroke, those recovering require access to rehabilitation and other recovery services. Aboriginal Peoples often have trouble accessing these services or are reluctant to do so for many reasons including previous negative experiences with health care services [8,9], or lack of cultural responsiveness by staff [9]. In addition, hospitalisation often involves time away from community and family, in highly isolating, unsafe clinical environments where Aboriginal Peoples experience suboptimal care [4]. This suboptimal care has been well linked to institutional and interpersonal racism with clear evidence of Aboriginal Peoples being less likely to receive basic investigations with higher rates of mortality and morbidity; whilst experiencing little follow-up after returning home [4]. Colonialisation is not an event in the past, but continues today through multiple layers of policies, practices and societal attitudes, reinforcing dominant Eurocentric views of health and wellbeing [4]. Often the difference between Aboriginal and non-Aboriginal views of health in clinical settings contributes to culturally unsafe care, marginalisation and ongoing miscommunication and disempowerment of Aboriginal Peoples and their families [4]. Importantly, to address stroke care needs with Aboriginal Peoples within our hospital and community health systems, Aboriginal views of health and wellbeing (holistic, connected and collective, not individual) need to be integrated and privileged in clinical care [10]. Importantly, Aboriginal hospital health workers and community liaisons are integral component of culturally safe care and stroke recovery [4].

There is limited research on post-stroke recovery and the role of family, carers and community in the experiences of Aboriginal Peoples. Family and carers have an important role to play in supporting the Aboriginal person who has experienced a stroke when they do return home [11]. Within Aboriginal health discourse, it is well evidenced that family and community is an important protective factor for an individual's health. Importantly, Aboriginal people's health being holistic, an individual's health and wellbeing is inseparable to the connection with family and kinship systems [10].

This study is part of the *Yarning up After Stroke Project* funded by the Medical Research Future Fund. The latter part of the study is a trial to co-design and evaluate a culturally appropriate stroke recovery self-management tool. The project commenced with studies seeking to provide an in-depth understanding of the current issues experienced by Aboriginal stroke survivors, their families, and carers, and by health workers supporting stroke rehabilitation and recovery support of Aboriginal stroke survivors living on Gamilaraay/Gomeroi country. The aim of this part of the study was to explore the experiences and perceptions of Aboriginal Peoples who have lived experience of stroke or lived experience of supporting a person living with stroke. This paper privileges the voices of Aboriginal stroke survivors and their families.

Method

Design

A qualitative descriptive (QD) approach was adopted for the study. The QD approach assists the researcher to remain in close contact with the data and assists to focus the research clearly on the experiences of the participants [12]. The research methodology was driven by an approach that respects Indigenous knowledge and worldviews; it also recognises that previous research has tended to be done *to* rather than *with* Indigenous Peoples [13]. To ensure the methodology respected Indigenous research principles of knowledge, world views and Indigenous voices, the study was guided by a local Aboriginal Cultural Advisory Group (ACAG) that includes Elders, community members and local Aboriginal health service providers. The research team consisted of seven Aboriginal and three non-Aboriginal members, who collaborated closely with the ACAG to co-design the study, conduct the data collection and undertake the data analysis. Importantly our work was informed by Indigenous research principles and acknowledges that stories and experiences are shared and negotiated at every step in the pursuit of knowing [14]. Details on how this project was guided by Indigenous research principles outlined in our CONSolIDated critERtia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement (see Supplemental Material #1). To privilege the voices of stroke survivors and community members, we adopted a yarning approach to data collection [15]. Yarning approaches are respectful and embedded into Aboriginal ways of knowing, being and doing, with the intent to ensure the research outcomes and stories are led by participants continually.

Setting and sample

Participants ($n = 17$) included in the study were Aboriginal Peoples living with stroke ($n = 6$) and family members and carers ($n = 11$) of people who had experienced a stroke living in the Tamworth area of New South Wales, Australia, on Gamilaraay/Gomeroi country. Three local Elders participated in the study. On Gamilaraay/Gomeroi country, Aboriginal Peoples make up a higher proportion of the population compared to other areas of Australia (local 10.1% - rest of NSW 2.9%) [3]. Table 1 provides unique identifiers and other information. Some information is not provided to ensure participant anonymity is maintained.

Recruitment procedure

Recruitment occurred through engagement activities within the local communities and referrals through local health services. Participant Information Sheets were co-designed by the project group which included Aboriginal Peoples living on Gamilaraay/Gomeroi lands who have had a stroke, Aboriginal researchers and an Aboriginal Speech Pathologist. The Participant Information Sheets outlined the aims and objectives of the study and the requirements of participants were presented to potential participants *via* these groups. People who agreed to participate in a yarn and met the inclusion criteria were asked to verbally consent to participate in the study prior to the yarn.

Data collection

Yarns took place between September 2022 and December 2022. Individual yarns were held at locations chosen by the participants and conducted by Aboriginal and non-Aboriginal researchers who were

Table 1. Participant information.

Identifier	Role	Sex	Age 65+
P01	Stroke Survivor	F	Y
P02	Stroke Survivor	M	Y
P03	Stroke Survivor	M	N
P04	Stroke Survivor	F	Y
P05	Family	F	N
P06	Family	M	N
P07	Stroke Survivor	F	N
P08	Family	F	Y
P09	Family	F	N
P10	Family	F	N
P11	Stroke Survivor	F	N
P12	Friend	F	N
P13	Carer	F	N
P14	Family	F	N
P15	Friend	F	Y
P16	Stroke Survivor	F	N
P17	Family	F	Y

members of the team. Most yarns were individual, with one group yarn conducted at a long-standing local art group ($n = 6$) with all yarns conducted in English. Prior to the yarn, the researcher's engaged in informal conversation with participants to develop rapport. Yarns were guided by a focused yarning schedule that addressed key topics identified by the team and the ACAG members (see Table 2 for an overview of the foci of the yarns). Most of the yarns lasted between 24 and 80 min. Audio-recorded yarns were transcribed by a professional transcription service with whom a confidentiality agreement had been initiated.

Data analysis

All transcriptions were loaded onto the NVivo12 platform (QSR International). JND led the data analysis with input from VB, SO, KU, and AT. Regular team meetings were held during the analysis phase. The ACAG were also involved in the analysis process. Following a thematic approach in-keeping with QD research [12], JND listened to all yarns and read the transcripts several times to familiarise himself with the data. The coding process was facilitated by the field notes and meetings with members of the research team including cultural guidance from Aboriginal research team members ($n = 5$). Meetings were conducted weekly *via* video link or telephone to allow for participation from all team members. Individual transcripts were analysed initially and then analysis proceeded across the transcripts and related themes were grouped to create superordinate and subordinate themes [16]. The final analysis was further refined with input from all team members to ensure peer validation [17] and to ensure input from the ACAG Representatives. For rigour and transparency purposes, provided below (See Table 3) is a sample of the data analysis process for one of the identified themes.

Patient and public involvement

Aboriginal Peoples living with stroke and their family, carers or friends were involved in the data collection phase of the study. Members of the Aboriginal Cultural Advisory Group were involved in all aspects of the study.

Ethical considerations

The Hunter New England Local Health District Human Research Ethics Committee (2020/ETH02782) and the Aboriginal Health and Medical Research Committee (#1773/21) provided ethical approval for the study. Prior to the yarns with participants, verbal informed consent was obtained.

Table 2. Yarning guide.

- Where are you from?
- Can you teach us what you and your community need to recover after a stroke?
- Can you tell me what helped you in taking charge of your recovery after stroke?
- Can you tell me what you think would help people who have a stroke in your community in the future to recover after stroke?

Table 3. Sample of theme development from codes identified in participant yarning interviews.

Theme	Codes	Reported in quotes
Disrespect and racism impacts stroke care access	Racism and ongoing colonial impacts on Aboriginal people engaging with health	7
	Colonial paternalism	2
	Racism in primary care	1
	Racism in hospital	3
	Racism and lack of cultural safety in rehab	1
	Staff lacked knowledge of Aboriginal health considerations	1
	Negative experiences and racism in hospital	4
	Safe respectful relationships are lacking in health	11
	Toll of racist community perceptions	5
	Lack of awareness and racism	1

Results

Four overarching themes emerged from our yarns: (i) The role of **family** in stroke recovery, (ii) **Trusted relationships with people aware of stroke and support** options, (iii) Importance of **culturally appropriate interactions** with health service, and (iv) **Disrespect and racism** impacts stroke care access.

Illustrative quotes, drawn from yarns with participants, have been used throughout the results, presented in participants' own words. It should be noted that the issues participants raised often represented a complex interaction with multiple health services, some good, some bad. As such, many of the quotes used below fell under multiple themes in our analysis. Similarly, participants often spoke about health interactions relating to other comorbid conditions. Where this had an impact on care experiences in relation to stroke, these interactions were included in our analysis. Figure 1 provides a visual representation of the structure of our major themes, reflected as subheadings throughout the description of results.

The role of family in stroke recovery

Participants highlighted the centrality of advocacy, support and healing provided by families and suggested that more needed to be done to include family in recovery discussions, and support and include family members who took on caring roles. Participants spoke about the importance of kinship in the recovery journey, both as a protective factor and as a cultural consideration that health providers needed to be aware of and respect.

> *"… if people have got their family around in close support it makes a big, big difference because you're not lying in a hospital bed in looking at the ceiling and thinking I'm all alone… you need a familiar face around you to help you in your recovery. Somebody that you know that you can talk to in confidence, and they understand where you're coming from…" (P02).*

The complexity of the role of the family unit was also highlighted. This was seen as both a huge source of support and a place in which the person living with stroke had responsibilities to care and provide for family members. The latter making it difficult at times to prioritise activities important for preventing and recovering from their stroke event.

> *"I just didn't know which way to turn, like, I knew I was unwell, but I had to wait that period of time and try and relax, where some people don't relax because they've got their great-grandkids to look after, or their own grandkids." (P07).*

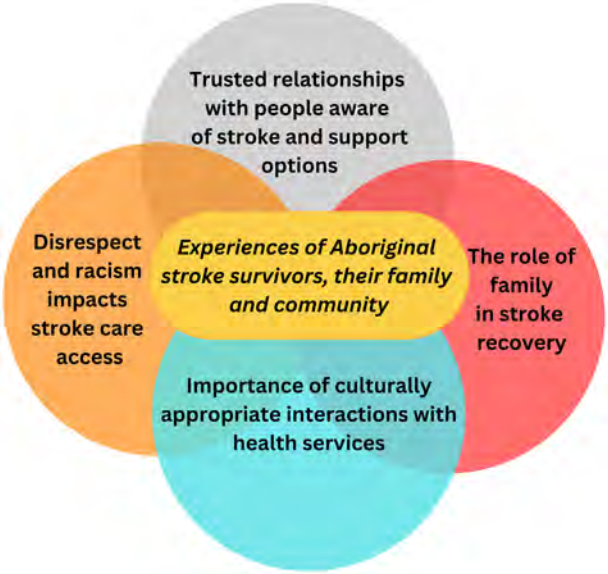

Figure 1. Major themes of the experiences and perceptions of first peoples of Gomeroi/Gamilaraay with lived experience of stroke.

The impact of stroke on family, both emotionally and practically, and what may have been helpful to support both the person living with stroke and their family, was often raised.

> *"…my husband had to take that load on of being a fulltime carer. …I would've found it valuable if someone did come in and just check on how we're going as a family with me being one minute okay and next minute not." (P01).*

Themes of pride and shame were also identified, with people living with stroke and family who cared for them often feeling shame at having to receive or give assistance with daily function.

> *"…he had a pretty embarrassing situation because my eldest daughter was staying with me and [Dad] … he sang out he needed to go to the toilet and by the time we got in there it was just too late. And then, yeah, and then after that he never come out [to home], never back out to visit even." (P08).*

A desire to shield family from distress led some stroke survivors to hide stroke events, symptoms, and issues, one participant stating, "*They didn't know I was in hospital… I didn't want my family to know. I didn't want to worry them" (P07)*. For some, pride and a desire for dignity also contributed to nondisclosure of symptoms.

> *"…I think Dad would've spoken to someone … Dad would've taken the opportunity, you know, one on one… But it has to be somebody that is trusted by community … 'cause I think he sort of saw the failing of his body as a failure, you know, and I think he became worried that this is going to happen to me" (P10).*

The presence of health issues in the community left some participants with reported feelings of worry and hypervigilance about their own health and the health of their families, further contributing to their feelings of stress but also motivating them to educate young people of the risks ahead of time.

> *"… heart problems are in the [family name] side of the family and it's basically that's why if I can reach all of them and say, 'You've gotta get tested, you've gotta do this, you've gotta do this'. You know what black fellas are like. We're all stubborn at the best of times" (P06).*

Trusted relationships with people aware of stroke and support options

Participants spoke about the importance of authentic support, relationships, and connection to their community in their recovery journey. For some, having people around them with good stroke awareness at the time they had their stroke enabled them to quickly receive care, resulting in better long-term outcomes. Some highlighted the benefits of receiving quick diagnoses and treatments, while others identified areas where delays exacerbated the severity of their stroke.

> *"So, when I had my stroke I rang* [stroke coordinator] *on the phone, and I said mate, I think I'm having a stroke. Well,* [stroke coordinator] *turned up straight away and she'd actually organised everything for me when I got to the hospital" (P02).*

Some found the lack of awareness around the consequence of not managing common risk factors for stroke frustrating. Others found the lack of understanding around post-stroke impairments difficult to explain when they were simply trying to recover and manage these changes themselves.

> *"So, I had to talk and say I'm not ready yet [to go back out into a community facing role]. So, I got a little bit frustrated, put it that way…I could feel a bit of pressure there, but I think with my stroke I felt a bit, trying to explain it was really hard, but that was because of the stroke" (P01).*

Similarly, having access to formal and informal support networks was seen as hugely protective and often meant people living with stroke were able to receive better advice and care due to a family member or friend expressing concern, solidarity, and motivating them to engage with health services and rehabilitation.

> *"…you need someone who … who, you know, basically is your partner on that journey, you know? … my friend and I, we're each other's partner along this journey, and we check in with each other all the time… Yeah, a buddy. You need your buddy to talk to about the good and the bad days" (P10).*

The need for ongoing connection to community and Country was also commonly expressed as a vital aspect of recovery. Community connections were often facilitated by participation in men's and women's groups. Mob only spaces for example arts and health groups were perceived as vital, where Aboriginal Peoples living with stroke and family members dealing with loss after stroke or stroke recovery without feeling pressure to speak about their stroke experience whilst connecting socially.

> *"…I'd go to our art group… that was just going along and having a yarn, but also doing something I really loved. I think it was the socialisation as well…I think that's so important. So, I think that was part of my healing process as well…*
>
> …[pressure to talk about stroke] *I didn't feel that at all, that was good. I think that's probably why I enjoyed it, people understood… because you don't want to be going back over and over and talking about it all the time" (P01).*

Connecting to Country was mentioned informally, typically as heading onto Country to visit culturally significant sites, or simply to spend time in nature.

> *"…it's important to go out with your mob or family out on Country. Just going down to the river and being with mob down the river, and that sort of thing" (P01).*

Importance of culturally appropriate interactions with health services

Whilst there were reports of good experiences of care after stroke, participants frequently identified instances where culturally safe care from health services were lacking. Consistent, authentic and culturally informed engagement and communication was frequently raised as a key requirement for health services to establish safe and respectful relationships with Aboriginal Peoples living with stroke. In the hospital setting, this typically related to receiving culturally safe care.

> *"… we could have used an advocate and a voice in there at that stage and we didn't have that" (P08).*

It was highlighted that ongoing communication, adequate information provision, and consistent effort to build meaningful and trusting relationships were vital ingredients for improving people's experience.

> *"So, it comes back to all people, not Aboriginal, if you don't know what they're talking about, well, how the bloody hell are you going to listen and take it in because you don't know what they're talking about. And the other thing is you're that angry with them that you're more likely to get up and that was a bad experience, don't ever take me back. So, then that person doesn't want to go back there because of that experience" (P02).*

Adequate follow up was seen as particularly important, with many participants reporting that the transition from hospital to community was made more difficult by lack of follow up with them and their family from hospital services, and limited linkage with community providers.

> *"I didn't really get much support from anyone at the hospital, other than a phone call… someone to come to see me at home and especially my husband as well, because for him it was a big shock as well because he was trying to care for me as well. …I wanted to come home, it's just that it would've been better if one of the community nurses or someone came out and just saw how I was going" (P01).*

One participant expressed frustration with the lack of in-person follow up and delays in accessing GP clinics or medical review following discharge from hospital.

> *"They should encourage it and say, 'Look, if you're not well, just come back and we'll do a blood pressure check,' maybe at the doctors surgery" (P07).*

Some felt that Aboriginal staff already working in liaison positions were unable to meet community needs due to structural barriers created by the health system that prevented them from establishing trust.

> *"… with our liaison officers and people working in the hospital system…they're not given the freedom to communicate with mob, the way mob like to communicate … they're supposed to come to hospital, that's not how [we]do things … have yarns, go and have a cup of coffee and just sit talk however long with these other people who are having issues, … that's not how the white system does it, so that's a big issue, especially with stroke recovery" (P12).*

Participants also felt that stroke survivors and people in community more broadly want trusted relationships with health workers who are of Aboriginal descent. However, they acknowledged that this is not always possible and that if not, health workers should be well trained in culturally safe practices. The need for consistency and the investment of time and energy into building rapport, to establish a trusting relationship, were considered non-negotiable aspects of post-stroke care.

> *"…[if] it's an Aboriginal issue we're not expecting Aboriginal doctors but we're expecting them to be trained to deal with Aboriginal People appropriately…having that awareness training of knowing our mob does things differently, and this is the way we do things, so please find that acceptable, don't come down on people who have got the right path, to see a physician… Someone with culture, someone with experience, whether it be mental health or nursing or first aid" (P14).*

These barriers were reported to result in delayed recovery while in hospital, with some participants feeling that people recovering from stroke would improve faster outside the hospital setting; but appropriate resources and support were not easily available.

Some participants reported positive experiences with rehabilitation, typically related to good communication and positive relationships with staff at all levels of care (including administration and cleaning), access to equipment and medications that improved ability to manage symptoms, and enjoyment of rehabilitation programs (e.g. hydrotherapy classes).

> *"…they rang me … the hospital, to see … how I was treated and everything, and I told them, because I can't text on my phone, and so I rang the hospital, and they said that they'd let 'em know [how] I was … I couldn't fault them in any way. They were lovely up there to me" (P11).*

However, all participants identified a need to improve the accessibility of rehabilitation services for Aboriginal Peoples living with stroke. Accommodation, inflexibility of rehabilitation offerings (e.g. inpatient vs outpatient), and unexpected disruptions to rehabilitation (e.g. due to staffing issues) were identified as barriers to successful engagement with rehabilitation services.

> *"Rehabilitation was useful but because of my condition very very slow, mostly I thought rehabilitation wasn't working for me, … [I] was informed that the hospital only offered rehabilitation to admitted hospital and current patients and [there was] no service for outpatients… I had one option to do everything by myself… I made it my business to be part of the rehab programme" (P03).*

Suggestions for improvement of rehabilitation services focused on provision of varied and flexible programs, including mob-only spaces and engagement in cultural activities.

> *"…I think some of the older Aboriginal ladies I think would love it [weaving]. And I mean for the men … to carve a didgeridoo. I would love to learn how to carve a didge… But other things like making boomerangs and the clappers and other different things that you don't see many much of anymore. And spears and things like that…if we could get a lot of them, get the old Elders to know where they're going and tell us, well I think you will find that you'll have more and more classes" (P06).*

Such cultural activities were perceived to create places where Aboriginal stroke survivors could feel safe and comfortable to engage in rehabilitation at their own speed.

Participants reported a desire for greater support to transition from hospital to community. Suggestions included encouraging and facilitating Aboriginal Peoples receiving rehabilitation in hospital to engage in community-based art/activity groups; providing home-based rehabilitation visits to facilitate earlier discharge; and having someone come by after hospital discharge to ensure they have everything they need for their recovery.

> *"… and come and do a … do a thing of your house, like, is there anything we need to change in your house to … because when Dad had his stroke, he couldn't talk as good for a bit, and he couldn't use his arm, but he had a quarter-acre block to mow, and a big house… and mum's health hasn't been good for years" (P10).*

Similarly, participants raised the need for centralised coordination of supports, to help stroke survivors and their families navigate the services that they require after hospital discharge and deal with various agencies to ensure their needs are being met.

> *"That whole… that's not coordinated very well… the amount of time that passes before even contact with the services. You know, you try to do it all but then it takes… like ACAT (aged care support) took months… and I think*

> *if you could have a set up… just have someone sit down and explain the whole process to you, and okay you mightn't take it all in…That's… that's where I think we need to know what, people need to know what's there" (P08).*

Assistance with managing finances, particularly immediately after a stroke, was raised as a key area of need. Developing additional resources to help Aboriginal Peoples living with stroke to consider the possible financial issues following stroke and explore options around return to work was also raised as an important consideration.

> *"The financial strain is one of the biggest things that people need to be aware of at the beginning, and they need help with. So, if you can get somebody in there to sit down, and the number one thing is to work out a financial budget. Because if you put things in place straightaway, it relieves that big crunch that people have come to when they've got no money, and you can't actually help them" (P02).*

In discussing recovery journeys, many participants spoke about the process of adjusting to changed capacity and building a new perspective on the value and purpose of their life. Often this journey involved periods of fear, trauma and denial as previously healthy people had to look to those around them for support.

> *"Of course I was worried; I was worried I was going to have a stroke again… That's another way Aboriginal People … I mean, it's my fault, I could have had it done sooner, but as in denial with a lot of my things that have happened, I did. I went into a bit of a denial thing… It's a terrible thing. Terrible journey to have" (P07).*

Some participants highlighted the need for services to recognise and facilitate this important aspect of the recovery journey, while others emphasised the importance of self-motivation and acceptance. The quote above elucidates the need to recognise and understand some people's sense of shame in having a stroke and what life might look like after stroke including acceptance of life after stroke as highlighted below.

> *"It [stroke] takes my independence away, even though I'm just retired, I'm still working, and I still want to help people. I've been helping people all my life, and if I can't get around to do that, it just takes away my independence and I don't know where I'm going to go. And it will affect my health. I know that because I'm a passionate bloke about helping people. And if I can't do that, and I can still get around, it makes me think then what's the bloody point of me being here? … I think the biggest thing is acceptance. When I accepted that I've had a stroke, there are things that aren't going to be" (P02).*

Finally, participants raised accessibility of services as a key factor in the facilitation of safe and respectful relationships between health services and Aboriginal Peoples recovering from stroke. This included having adequate access to mental health support to manage the psychosocial impacts that often arise, being able to access primary care in a timely manner and having transport options to facilitate access to services.

> *"And you need that support right from the word go because, in my experience, mate, I used to wake up at 02:00, 03:00 and burst into tears because I didn't know… I didn't know when the next one [stroke] was going to be and I needed people to actually talk to (P02).*

Disrespect and racism impacts stroke care access

Participants sometimes expressed a sense of fatigue and stress due to racist interactions and perceptions within the broader community. Peoples who experience racism often report higher rates of such instances, including fatigue from often needing to explain and address culturally unsafe care in health care system as well as vigilance and wariness of perceived racial behaviours [18]. Often leading to difficulties in receiving care and managing the symptoms of stroke. Highlighted below a carer shared their story on how they ongoingly navigate stereotypes associated with Aboriginal Peoples and potentially the impact this may have on care.

> *"Well see, Dad… He wasn't a daily drinker, whereas, you know, Aboriginal People … a lot of people think that they drink all of the time. No one in my family does. It's that stereotype, yeah, stereotyping, and they all assume you drink and smoke. No one in my family does (chuckles). Yeah, we're all very mild social drinkers". (P10).*

Experiences of poor communication, including lack of consideration for the cultural safety of patients and their families, due to perceived dismissive treatment and lack of information provision regarding medical procedures, symptoms, and recovery pathways were also described.

> *"I was in emergency, and I was transferred to the stroke ward when I was coming out of what happened to me … you know, no one had told me that I had high blood pressure… So, stayed in hospital overnight. They took the intravenous out… and I begged for that intravenous line to be kept in my arm, because I didn't feel 100%. So, the next day I thought, 'Well, I may as well go home, because the line … my fluids had been taken down at three in the morning and no one's listening to me (chuckles), so I may as well go home" (P07).*

Racism in rehabilitation and primary care was also reported, with similar negative impacts on engagement and recovery as in the hospital environment. Sometimes, these instances were described as outright bigotry and stereotyping. At other times they were described as a lack of cultural awareness and sensitivity training.

> *"Well see, Dad… He wasn't a daily drinker, whereas, you know, Aboriginal People … a lot of people think that they drink all of the time. No one in my family does. It's that stereotype, yeah, stereotyping, and they all assume you drink and smoke. No one in my family does (chuckles). Yeah, we're all very mild social drinkers" (P10).*

Another example of poor professional behaviours was highlighted when a participant shared her experience when pregnant and visiting her GP:

> *"…when I had my daughter…we had a miscarriage before her, when I went to a doctor, he said to me do you want to abort it, and I said no I don't and he said lets be realistic here you probably should have aborted the last two, one's more than enough…". (Art Group 1)*

Participants highlighted the ongoing impacts of colonialism on Aboriginal People's health and engagement with health services. Importantly, this quote below identified not only the historical consequences of colonisation, but also how Aboriginal Peoples engage with health services today:

> *"…if we're talking about Aboriginal People that have grown up on missions, and I'm talking about people in their 60s…their life was controlled from an early age up until the seventies. And stuff is still impacting on their lives today because they were told what to do, they were controlled… and they're lost in the system because they lay there, and they're too afraid to ask… they'd [people who have lived on Missions] been told all their lives what to do, they didn't know any different… I dealt with Aboriginal People here that had just had a stroke, the same old story, they've been too afraid to ask for help because no one's ever approached them" (P02).*

The impact of this disrespectful treatment resulted in some participants stating that they or their families were hesitant to attend health services and, how this might impact others in attending a health service, particularly if families have experience previously mistreatment or racial harm:

> *"…I've seen this from ever since I was a young kid going to hospital, they'll come out and the Aboriginal People will talk amongst themselves and don't go up there because they're not worth going to. So, that spreads like wildfire, and the important thing is to make this community connection" (P02).*

Based on this hesitancy, one participant suggested that having an impartial advocate to help people navigate the health system would enable Aboriginal Peoples to ask for help and receive an acceptable standard of care.

> *"… but I think had I had someone there that probably could have been a more rational voice for me, or at least then we felt we were being listened to, and then if there was a reason why they hadn't sent him for the MRI, come back and say to us, not just fob us off" (P08).*

Discussion

The study was conducted to explore the experiences and perceptions of people with lived experience of stroke and those caring for those with stroke in the regional community of Tamworth, New South Wales, Australia; on Gamilaraay/Gomeroi Country. Yarns revealed the importance of involving family in all aspects of an Aboriginal stroke survivor's care (i.e., acute through to discharge back into the community), and the impact that culturally safe care, racism and disrespectful treatment has on access to and engagement in stroke care. Importantly to maximise recovery, this study's results highlight the influence that an Aboriginal person's connections to stroke aware people and their community and Country plays in seeking both acute care and ongoing rehabilitation.

Many of the themes and experiences emerging from this study's yarns and additionally yarns conducted with health workers [19] echoes that from yarns conducted with stroke survivors, carers and other stakeholders including health workers, living in the Northern Territory, South Australia [20], Far North Queensland [21] and Western Australia [22]. For example, the importance of appreciating the; role that family involvement plays in recovery, and the influence of conflicting priorities and problems arising from a poorly coordinated discharge and/or the complexities of navigating the stroke recovery journey. Our study which utilised in-depth yarning methods, builds on this knowledge consistently revealing experiences where Aboriginal stroke survivor experiences of a stroke care that was not culturally safe, became a barrier for stroke survivors to seek help, remain in inpatient rehabilitation, receive quality co-ordinated community-based services, and in some cases, prevent long-term engagement in rehabilitation activities. Furthermore, our yarns revealed suggestions on what may be supportive for stroke survivors of the future within this community.

The compounding complexities experienced in accessing culturally responsive health care services including eligibility, awareness and access may be alleviated and/or improved by a care coordinator or 'navigator'. Armstrong et al. have highlighted the potential success of a care navigation role in the support of patients and families with brain injury recovery including stroke. This study highlighted the importance of the need for specific health education, support and advocacy for Aboriginal patients and communities. The person employed in a 'navigator' role being one who is a trusted community member and who is available to help support the stroke survivor and their family from initial stroke onset; a person who is aware and knowledgeable of stroke and culturally safe services, and who with this knowledge guides the stroke survivor and their family through complex health systems. The overarching goal of this 'navigator' would be to strengthen the stroke survivor's (and/or family) capacity to self-determine their stroke recovery care and long-term health and well-being after stroke. Importantly we have also identified in the results of this study the navigator must be critically conscious of the consequences of culturally unsafe care for the person living with stroke and their families. Whilst participants of this study did not explicitly state whether the person within this navigator role must be Aboriginal, evidence from the literature indicates that there would be many advantages to this being an Aboriginal person [23] Decisions about this and other characteristics of the role must reflect the wants and needs of the Aboriginal Community for whom this 'navigator' will support and this in combination with ensuring extensive and ongoing authentic consultation with the Community, is of the utmost importance.

The result of this study highlights the importance of understanding the experiences of both the person who has had a stroke and their family/carer. Health workers need to understand the complexity of relationships and family dynamics that can be significantly and negatively impacted by serious illness such as stroke [24,25]. This is especially so when Aboriginal Peoples and families are involved.

In this study we heard many stories of survivors discharged home to be cared for by partners and/or family with insufficient preparation or support. Stroke survivors have previously described being discharged home with a variety of unmet needs such as mobility and communication, understanding of recovery potential, organised interaction with healthcare professionals, medicines social and emotional wellbeing [26,27]. However, discharge preparation should prepare the survivor and their partner/family/carer for the transition to home. When this occurs effectively, better outcomes are experienced by the survivors and their partner/family/carer [25]. In some situations, described in this study, the expectations placed on partners and families was not in-keeping with what the partner or family members had the capacity to provide. Studies of stroke survivor experiences in other contexts have also reported this finding [25] and described situations where family perceptions of the caregiver role differ to that of others outside the family unit [28]. Previous research has reported that family members express how outsiders lacked awareness of the actual demands placed upon them as caregivers, with health workers often assuming that the partner/family members have both the ability and desire to provide care for the stroke survivor [28]; this is not always the case [29]. It is important that health workers understand the patient and family social context in preparing for recovery and ongoing care needs after discharge from hospital. Regular involvement of family and kin in recovery discussions and management, as highlighted in our study, may provide opportunities to prepare family and kin well, and importantly, strengthen their confidence in supporting the person with stroke when they return back home and participate in their community.

The elevated risk of developing health problems among Aboriginal Peoples can be understood as a cultural, social and epigenetic consequence of the early and ongoing impacts of colonisation over the last 250 years. Colonial disruption of Aboriginal cultural practices, connection to Country, social structures, ways of knowing and diet (*via* provision of processed foods as rations on missions, such as sugar, flour, bread, tobacco, and alcohol) have created intergenerational risks due to entrenched social, political and economic inequalities, genetic vulnerability to the negative impacts of Western diets, and epigenetic changes associated with trauma and chronic stress associated with historical and ongoing discriminatory practices. Colonisation continues to shape the health and wellbeing of Aboriginal Peoples and communities. The impacts associated with colonisation are presented not just within stroke survivors and families today but have been a generational impact since the beginning of invasion with reports of premature illness going back generations and across the family tree, as highlighted in this study [30].

The cumulative effect of past experiences of racism and dismissive treatment compounded with present negative experiences has had, and continues to have, a detrimental toll on Aboriginal Peoples and their willingness to seek health care and engage with services. It is well documented in the literature that Aboriginal Peoples are exposed to negative behaviours and treatment at systemic and individual levels when accessing healthcare [31]. Within the results, internalised racism was not identified, however alike institutional and interpersonal racism, internalised racism impacts Aboriginal Peoples health and wellbeing and occurs through the adoption of negative beliefs held towards Aboriginal Peoples [32]. As highlighted in the results however, clinicians portrayed some of these beliefs and like the participants of this study, experiencing racial attitudes from healthcare staff, effects of racism on treatment options, being viewed as difficult, and being dismissed in healthcare interactions [33], contributes to Aboriginal Peoples of Australia avoiding accessing available healthcare services. Negative experiences, not being believed and being disrespected contributes to mistrust and reluctance to seek medical help or advice for their symptoms, which can have a detrimental effect on stroke recovery when we know that time is brain [34], the sooner treatment is sought and received the better the outcome both functionally and in terms of long term-wellbeing.

Within the literature one of the lasting and continuing impacts of colonisation is racism particularly in relation to Aboriginality of being a problem to be solved where scholars have highlighted the internalising effects of individuals and families seeing themselves as a problem [5]. Importantly key to stroke recovery for individuals and families as highlighted by the results of our study, people living with stroke and recovery depends on the healthcare system (primary and tertiary settings) the supports around them to enable a quality life after stroke guided by their health needs within the lens of social and emotional well-being for Aboriginal Peoples [35].

Strengths and limitations

The small qualitative study included Aboriginal Peoples and their family/carers/friends from a specific location in Australia. Aboriginal Peoples are not homogenous in their experiences or beliefs, so context specific understanding is essential. Whilst this is a strength of the study it is also a limitation as the generalisability of the findings to other Aboriginal Peoples of Australia is not necessarily possible. Further research is needed to determine whether similar experiences are relevant to other Aboriginal Peoples of Australia or Indigenous Peoples across the globe.

Implications for clinical practice

These findings have implications for health staff involved in delivering stroke recovery care to Aboriginal Peoples throughout all stages of the stroke journey; from initial presentation to the emergency department, within the hospital inpatient setting and importantly when transitioning to and living within, their home and community with their family and support people. Importantly, health staff must recognise the historical consequences of why Aboriginal Peoples may delay presentation to hospital (e.g. negative experiences when presenting to emergency) and/or stay within the hospital setting to receive their post-stroke rehabilitation. Secondly health workers need to incorporate Aboriginal families into the care and recovery of the person post stroke. This will ensure patient and family priorities are at the centre of care and enhance the person with stroke to self-determine their stroke recovery. These findings are also relevant to health and social service teams who offer ongoing support to Aboriginal Peoples newly diagnosed with stroke and their family/carers. To ensure appropriate and timely referrals, connection with groups aimed at strengthening social and emotional well-being, and support from services that specialise in supporting people with financial and social implications post stroke.

Conclusion

The aim of this study was to privilege the voices of Aboriginal Peoples and their families living with stroke. A stroke event within this Aboriginal community had a ripple effect; the experience of stroke affected not only the person having a stroke, as well as their family and community connections. Ensuring the patient and family remained informed and centred within stroke recovery care plans will strengthen the person and family's self -determination to imagine and thrive after stroke. The healthcare system is complex, and decision-making options are not always well defined; the complexity and unclarity of the system resulting in decisions on care often being made by health workers rather than the stroke survivor and/or their family. Furthermore, the systemic racism that is frequently experienced by Aboriginal stroke survivors may be best combated with upstream interventions such as policy changes and place-based interventions that facilitate collaborative solutions that make services more appropriate and accessible. In addition, social determinants of health drive inequities across many aspects related to stroke and require researchers to deliver innovative interventions to mitigate these barriers to effective stroke rehabilitation services in the community. Importantly, we need to ensure to privilege the voices of Aboriginal Peoples living with stroke and their families with the healthcare system so that their care is defined by them and is relevant to their social and cultural contexts.

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Ethics approval

Ethical approval to conduct the study was received from the Hunter New England Local Health District Human Research Ethics Committee (2020/ETH02782) and the Aboriginal Health and Medical Research Council (#1773/21). Written informed consent was obtained from all participants in the study.

Contributors

All authors were involved in the design and conduct of the study with Elders NS, AT and JM providing cultural guidance throughout. VB, RS and SO worked closely with JND, HJ, NC and KU to provide cultural context during analysis of the yarns and refinement and led the interpretation of results and formation of the final themes. All authors contributed to the write up of the results verbally or by editing the final manuscript.

Participant consent for publication

Participants agreed to publication of results and inclusion of anonymised quotes at the time of consent.

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Data availability statement

Data from yarns gathered for this study are not freely available.

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