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TITLE: **"You felt like a prisoner in your own self, trapped": The experiences of Aboriginal people with acquired communication disorders**

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Abstract

Purpose: Aboriginal Australians are under-represented in brain injury rehabilitation services despite a high incidence of both stroke and traumatic brain injury in this population. This study aimed to explore the experiences of Aboriginal Australian adults with acquired communication disorders after brain injury for the first time to inform the development of accessible and culturally secure service delivery models.

Methods and materials: Semi-structured interviews were undertaken with 32 Aboriginal people who had experienced a brain injury resulting in acquired communication disorders (aged 35-79 years) and 18 family members/carers across Western Australia. Thematic analysis identified common themes across participants.

Results: Overall themes related to communication (both related to the communication disorder and general healthcare interactions), health and social contexts, recovery and support, being away from family and country, knowledge and beliefs about brain injury, and follow-up.

Conclusions: An increase in healthcare staff's appreciation of the health and social contexts of Aboriginal people after brain injury is needed in order to improve communication with Aboriginal patients and the ability to offer accessible rehabilitation services. Ongoing support is required, with cultural identity noted as key to ensuring cultural security and ultimately recovery. Involvement of family and other Aboriginal people in recovery processes, as well as access to relevant Aboriginal languages and proximity to ancestral lands is central.

Introduction

Aboriginal Australians are known to suffer acquired brain damage as a result of stroke or traumatic brain injury (TBI) at higher rates than non-Aboriginal Australians [1, 2, 3, 4, 5] and yet representation of Aboriginal people in ongoing brain injury rehabilitation services is low [6, 7, 8]. To date, little is known about Aboriginal peoples' ongoing experiences of the effects of brain injury on their own and their family's life. Similarly, the nature of rehabilitation services offered and reasons for under-representation have not been explored. In order to understand Aboriginal peoples' experience of brain injury, it is essential to take into account the importance of positioning health within a far broader social framework that reflects both a cultural and a biopsychosocial view of health and wellbeing as well as examining the adequacy of current services. A social model of disability, advocated for in the Indigenous context for a number of years [9, 10], also highlights the need to understand different constructs related to the consequences of brain injury. For example, several authors e.g. Gilroy [9], Avery [11] discuss the absence of a concept or term similar to the English term 'disability' in Aboriginal languages and the way(s) in which society largely determines these consequences, rather than the brain injury or the nature of the condition itself. In a social model, the role of family, community, and the views of the broader society intersect with factors such as socio-economic status, living arrangements and spiritual beliefs to influence the impact and experience of the brain injury and a person's recovery. To date, there is limited documentation on Aboriginal constructs surrounding the physical, behavioural and cognitive consequences of brain injury specifically. This paper attempts to explore such constructs through hearing the Aboriginal person's experience first-hand. Understanding peoples' experiences of current health services as well as the broader context, is essential to improving healthcare for Aboriginal people with brain injury.

Access to services is reported as problematic for many Aboriginal people, with barriers identified as communication breakdowns, racism and distance from established services in regional and remote contexts [12, 13, 14, 15]. However, with the exception of a small number of studies [12, 16, 17, 18, 19, 20] most have investigated Aboriginal and non-Aboriginal health professionals' perspectives on the issues involved rather than that of Aboriginal patients themselves. The importance of obtaining the Aboriginal perspective is increasingly acknowledged as part of service focus on client-centred and family-centred care. Inclusion of Aboriginal voices and leadership in research surrounding Aboriginal health is also crucial [21] and consistent with a growing body of work recommending the privileging of Indigenous voices in any research involving Indigenous peoples [9, 22, 23]. Nevertheless, people with communication difficulties are still often excluded from such studies due to a perceived inability to participate despite many having the ability to communicate.

Findings from a pilot study interviewing Aboriginal people with an acquired communication disorder (ACD) after stroke and their families [6, 24] revealed that few Aboriginal people received rehabilitation treatments or supports following discharge from hospital. Some received short-term rehabilitation and wanted more, while others did not connect with outpatient rehabilitation services, hence did not receive regular services. Some Aboriginal participants were managing with severe communication problems, either alone or with the support of family. Many simply 'got on with life' as best they could and were unaware that supports were available; for example the person who had suffered the brain injury, their family and community often had limited knowledge about brain injury and its consequences or an understanding of where and how assistance could be sought. Many felt unable or were disinclined to re-contact the hospital for support after discharge.

Guided by findings from our pilot research which encompassed the stories of Aboriginal people with brain injury and their families from a range of demographic and geographical contexts,

and with the support of Aboriginal Community Controlled Health Services throughout Western Australia (WA), the current findings formed part of a larger mixed methods study, *Missing Voices* [25]. *Missing Voices* investigated the extent and impact of brain injury on Aboriginal Australians using analysis of linked data of hospitalisations and mortality, file audits and interviews with key stakeholders including Aboriginal people who have experienced a brain injury, their families, and health service providers. This comprehensive approach aimed to inform development of appropriate, culturally secure adult brain injury rehabilitation service delivery models. In this context, cultural security refers to ensuring that Aboriginal cultural values, world views and ways of working are incorporated at each level and stage of the rehabilitation service and that services will not compromise the legitimate cultural rights, values and expectations of Aboriginal people [25].

The Western Australian context

The Australian Aboriginal and Torres Strait Islander (the First Australian) population constitutes 3.3% of the total Australian population [26] and consists of numerous different cultural groups, with more than 120 separate Aboriginal languages spoken (240 at the time of colonisation) [27]. WA is the largest state of Australia covering 1,021,478 square miles across coastal and vast inland regions, ranging from Mediterranean to tropical to desert climates. WA is relatively sparsely populated except for one metropolitan area (Perth) and seven broad regional areas. Forty percent of Aboriginal people in WA live in metropolitan Perth, while approximately 38% live in remote or very remote communities, as defined by the Accessibility/Remoteness Index of Australia-Plus [28]. Our recent work [29] has revealed that 56.4% of Aboriginal people who have suffered traumatic brain injury live in remote or very remote areas, compared to 10.6% of the non-Aboriginal population. Rehabilitation services are largely centred in the Perth metropolitan area, with many people flown thousands of miles to Perth from rural and remote communities after their brain injury.

Aboriginal Research Framework

In embarking on the current study, a number of principles were adhered to that aligned with an Aboriginal Research Framework as described by [30, 31] for health contexts, and also incorporated central notions of Indigenous Standpoint Theory [9, 32] which guide research that deals with Indigenous peoples more generally. These include inclusion of/leadership by Aboriginal researchers in the research team, acceptance of colonisation as a social determinant of disability, acknowledgment of the diversity of Aboriginal peoples, use of local languages, and Aboriginal community capacity building. Aboriginal research team members and an Aboriginal Reference Group including Aboriginal people who had suffered brain injury and family members, Aboriginal health workers, health administrators and disability advocates guided the *Missing Voices* study throughout in terms of cultural security. The study was conducted in partnership with Aboriginal Community Controlled Health Organisations and local Aboriginal Health Planning Fora throughout WA and Aboriginal interviewers were employed and trained as part of the data collection to be outlined below. All aspects of the study also aligned with the National Health & Medical Research Council (NH&MRC) Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research [33].

The aims of the current study were i) to explore the attitudes and experiences of Aboriginal people with brain injury after both stroke and brain trauma across WA, ii) to explore their experiences of having a communication disorder in everyday life, the support/rehabilitation services accessed, and how such services could be improved, and iii) to utilise the above to inform new models of service delivery.

Materials and Methods

Participants

Participants were recruited from six different regions in WA – the Kimberley, Pilbara, Midwest, Goldfields, Great Southern, and the Perth metropolitan area. Participants had to have a diagnosed ACD i.e. one or more of the following - aphasia, dysarthria, dyspraxia, cognitive communication disorder. Participants were at least three months post onset of ACD, incurred as a result of either stroke or TBI, and were over 18 years of age. Both males and females could be recruited. Referral to the study and invitations to participate occurred through Speech Pathologists, Aboriginal Health Workers, General Practitioners, community members and through the networks of the Aboriginal Reference group. A local Aboriginal person was employed within each area to facilitate this process. Relevant family/friends/caregivers were also invited to participate.

Consent

Consent was obtained from all participants using aphasia friendly consent forms designed to assist those with aphasia and those for whom literacy might be limited. Supported conversation techniques [34] were used to ensure that each participant with brain injury understood what was required and what was involved in the research. This was embedded in a yarning framework which encompasses a relaxed, culturally appropriate conversational style [35]. Only one participant required an interpreter or family member to translate for them during this process. The services of an interpreter were utilised if i) the person spoke no English, ii) the person spoke some English but their first language was an Aboriginal language and they requested an interpreter.

Data collection

Interviews were undertaken by Aboriginal interviewers trained in yarning methods of semi-structured interviews and in using supported conversation techniques for people with ACD [34] and utilising a yarning framework [35] as described above. On occasion, these interviewers

were accompanied by one of the speech pathologists associated with the research team when the type/severity of the ACD was considered sufficiently challenging to an interviewer so that support might be needed (this occurred on ten occasions). Open-ended interview questions ranged from broad questions about the participant's experience of the stroke/TBI initially, to questions about therapy, family reactions, and longer-term experiences and reflections on assistance received (see Appendix 1). Interviewees were given a choice of where interviews would be conducted to ensure participants were comfortable. Thirteen interviews were completed with family members/carers present, three were completed with family members/carers separately. All interviews were either videotaped or audiotaped depending on participant consent.

Data analysis

Interviews were audio or video-recorded and transcribed verbatim. Initially, one non-Aboriginal researcher listened to all audio-recordings and coded all transcripts, identifying themes and adding thematic categories until reaching saturation. A second (non-Aboriginal) researcher analysed 25% of the data independently, also coding for themes. The texts coded by the two analysts were discussed and consensus reached on themes. Individual analysts also made notes (memos) on transcripts as well as reflections on codes. Much of the data were dialogic, and the thematic analysis included both the contribution of the person with ACD and their family member or carer when present, with the themes combining the contribution of both individuals. Separate thematic analysis of each participant's contribution was often not possible in cases where a family member was present due to both the nature of the data (dialogue) and the co-construction of many of the points made, reflecting the nature of the ACD and assistance given to the person with ACD by their family member.

The initial themes were discussed with an Aboriginal research team member for further analysis and verification. This was to ensure that interpretations were accurate and that thematic categories were culturally appropriate and reflected speakers' intentions as shown in the transcripts and video recordings. Through this process, adjustments to interpretations were made through consensus, dispute of proposed themes was resolved and new themes raised. The resulting initial themes were then discussed with the other Aboriginal and non-Aboriginal members of the research team. The group looked to see which themes or codes could be merged, then formed consensus around major themes and sub-themes.

The data was approached utilising a framework based on Bronfenbrenner's socioecological model [36]. This model reflects the way(s) in which the individual is inextricably interwoven with their immediate contexts, while also remaining embedded in wider community systems and ultimately macrosystems of culture and society. The framework for our current study demonstrates the specific embedded nature of the relationships between the individual with the brain injury, service providers, family, and broader community, all influencing and being influenced by general societal/political/cultural attitudes and values. In this model, the person with the brain injury is at the centre, embedded within the increasingly broader contexts as depicted in figure 1 [37]. The model aligns with an Aboriginal world view which also acknowledges the inter-linking of components that all significantly impact and shape one's journey in life – in this case the journey of the Aboriginal person after brain injury.

Ethics

Ethics approval for the project was granted by the Western Australian Aboriginal Health Ethics Committee, the Human Research Ethics Committees of Edith Cowan University, the University of Western Australia, the Western Australian Department of Health, the Southern

Metropolitan Health Service, the Western Australian Country Health Service Research Ethics Committee, and the Kimberley Aboriginal Health Planning Forum Kimberley Research Sub-Committee. Approval was also obtained from four Boards of Aboriginal Community Controlled Health Organisations, and one Western Australian Country Health Service-managed Aboriginal Health Centre.

Insert figure 1 here

Results

The study recruited 32 Aboriginal people with ACD at least 3 months post-stroke or TBI and 16 family members/carers across the six different regions with a minimum of nine language groups represented. More participants had experienced a stroke than a TBI (table 1). Eight participants had aphasia, five had dysarthria, two had cognitive communication disorder, seven had more than one disorder, five reported 'slurring of speech' initially which had since resolved, and one reported aphasia that had resolved. Of the 32 people interviewed, communication disorder was confirmed from medical notes for 29 (91%) of participants and by self or other report for three remaining participants. A range of family members/carers participated (see table 2).

Insert table 1 here

Insert Table 2 here

Thematic analysis

An overarching theme that emerged from the stories surrounded communication – communication between the person with the brain injury, their family and hospital staff, as well as communication between the individual and their family network, friends and work colleagues. There were communication issues specifically related to the person's communication difficulty, there were 'general' cross-cultural communication issues, and of course, there were issues that involved both. Several other themes and subthemes related to social context and health comorbidities, beliefs and attitudes around brain injury, and issues related to recovery such as the effect of brain injury on their identity, employment, and desire for independence which reflected the practical challenges they experienced. The impact of being away from family and 'country' on follow up and support mechanisms also emerged – see table 3. In an Aboriginal context, 'country' refers to more than a physical area or region the person may come from. As cited in Porr [38]:

"People talk about country in the same way that they would talk about a person: they speak to country, sing to country, visit country, worry about country, feel sorry for country, and long for country. People say that country knows, hears, smells, takes notice, takes care, is sorry or happy. Country is not a generalised or undifferentiated type of place, such as one might indicate with terms like 'spending a day in the country' or 'going up the country'. Rather, country is a living entity with a yesterday, today and tomorrow, with a consciousness, and a will toward life. [39].

Insert Table 3 here

While categorising themes across the data set enables generalisations to be made, the analysis also focused on the richness of many of the individual participants' stories to reflect

experiences more fully. For this reason, we have retained many quotes as part of the narrative of this paper rather than representing Aboriginal voices outside of a narrative context and depicted in relative semantic isolation. Pseudonyms are used throughout except where participants indicated their real names were a preference in any publications.

Communication

Specific issues related to communication disorder. *Anger, frustration and powerlessness.* Feelings of anger and frustration related to the communication disorder were common. Some people felt they were not the same person - a lesser person than before the injury, and stressed the importance of recovery from the ACD alongside physical recovery:

> *You kind of feel powerless.   Ah, when words are slurred it was like, nobody could really understand you and, they drew their own conclusion.   But you ... you really did feel like a prisoner, in your own self, trapped.* (Ruby, 48 year old, stroke 12 years earlier, living in regional town)

> *Well, the hospital did... the ramps.   But the speech needed to be better. ....and it's funny because speech is actually more important than being able to move around, walking.* (Bess, wife of 42 year old man who suffered a stroke 11 years earlier, living in metropolitan area)

Change in identity. The participants also noted a change in the interactions between themselves and family /care providers, including their feelings of anger towards self and others. The people who had experienced the brain injury also felt that others, including their family, perceived them very differently, affecting roles within the family and personal/social identity:

Cos he was always takin' the kids to their training all the time…. then when he had this it stopped. He wouldn't go anywhere. So I think… yeah the bond between father and sons sort of just went, yeah… (Bess, wife of 42 year old person after stroke, stroke 11 years earlier, living in metropolitan area)

*I've been independent all my life, you know. I was … I'm a superwoman, you know. And it suddenly hit me that I wasn't the strong woman that I thought I was, I think. Because to me for someone to have a stroke, there's a sign of some kind of weakness. And that's the way I felt. (*Lorraine, 79 year old, stroke 2 years earlier, living in metropolitan area)

Misdiagnosis. Aboriginal language usage was also a theme, with points raised related to confusion between Aboriginal language usage and the diagnosis of an ACD as well as the importance of language and culture. In one case, medical staff assumed a patient, who grew up in Perth and whose first language was English, did not speak English when he was producing aphasic jargon, leading to an incorrect diagnosis. For another participant, staff at his aged care facility assumed he was speaking 'jibberish', due to his severe head injury and dysarthria, when he was actually speaking his local language:

"And I think that um maybe in the nursing home when he was talking, he was talking language and people just presumed that he was talking jibber but I think perhaps he was talking language, which is you know losing your voice in a different way isn't it? (Carer of 60 year old man with a TBI, motor vehicle accident 20 years earlier, living in regional town)

Similarly, a 74 year old woman (Winnie) with severe aphasia post stroke, from a remote area, was initially judged by nursing and medical staff as having adequate skills in 'Aboriginal

language' with the following observation recorded in the medical notes: "Pt able to communicate well with family in Aboriginal dialect." However when an interpreter, speech pathologist and Aboriginal Liaison Officer undertook a full language assessment together, it was found that in fact she was only able to use 5-10 words from her Aboriginal language. This enabled an accurate diagnosis followed by explanation of her communication needs to family and other hospital staff.

Importance of language in the context of having a communication disorder. The importance of language and culture was also highlighted within the interviews, one partner of a participant with ACD explaining that he and his partner experienced culture shock when she was flown to the city from a rural town and they were challenged by not being able to speak their own language. Another carer commented on the difference hearing 'language' (an Aboriginal language) made to the person she cared for who had very little speech but could follow conversation:

> *When [name of person with TBI] has visitors that speak language…. Um, the laughs and the difference and the communication and the talk- is, is really, is really good! It makes a difference. ... And [name] is um ... more engaged and he starts to talk more and you know he's happier.* (Carer of 60 year old person with TBI, motor vehicle accident 20 years earlier, living in regional town)

Winnie (noted above), who typically appeared very quiet and expressionless in the nursing home, became very animated in one session with an interpreter, using some sign language and facial expression to actively engage with the Aboriginal interviewer– something she had rarely done previously.

Stereotyping. Staff stereotyping a patient having a stroke on admission to Accident and Emergency based on the person's slurred speech clearly interfered with communication initially and demonstrated the effects of potential racist attitudes on emergency treatments:

> *Well, what she [the nurse] said to her [another nurse] was, "How do they get that drunk this early in the morning?" because it was just nine o'clock in the morning and A (wife) said to R (daughter), "Grab a wheelchair quick," then to the nurse " He doesn't drink." And I don't drink. I haven't had a drink since I was 17 and I'm now 64 - you do the math.* (Louis, 64 year old, stroke 6 months earlier, living in rural town)

General Communication Issues. Communication between Aboriginal people who had suffered a brain injury, their families and largely hospital based health professionals was a common theme throughout, with stories encompassing both positive and negative experiences. Besides ACD-specific issues, communication issues are also linked to the way(s) hospital staff and family relate to the person and to each other, within the context of the hospital setting itself. The fact that language and communication disorders overlay these more general issues further complicates this crucial component of care. Concerns raised were grouped as a number of sub-themes and expanded upon below.

Medical jargon and information overload. A common experience related to the way information was conveyed by medical staff. Participants talked about information being unclear to the person with the brain injury and/or their family, as well as too much information being provided at one time.

Half the time you've got this white fella there and they're giving you the technical side of it or the medical side of it and you haven't got anybody there to advise you ... like, an explanation of what that's all about. I'm not illiterate, you know, I know white man's talk. I know how to talk back to them. But sometimes you get these men that they get ... or women ... they just go on and on, you know. You feel like saying, "Will you shut up for a minute?" (Lorraine, 79 year old, stroke 2 years earlier, living in metropolitan area)

Type of information needed. In addition to information related to medications and appointments, people who had experienced brain injury and their families wanted practical information on how to live with their disability including such aspects as managing behavioural problems, personality changes, and communication issues. They commented on the amount of medical information they received, particularly related to appointments after discharge, but suggested that information related to 'coping with life' and practical assistance options would have been useful. A wife of one participant reported that they hadn't learned about a social service card they could have accessed or a disability advocate service until six years after discharge from hospital. However, appreciation of clear explanations of stroke obtained from health professionals was evident – in this case from a neurologist:

Well, he told me what was happening to me eh, and what was affecting this stroke to my brain, you know..? It was the knowledge I was looking for, you know? (Sally, 72 year old, stroke 7 years earlier, living in regional town)

Some participants also suggested that more educational material and support for family and young children was needed.

Yarning, humour, and support. One speech pathologist was especially praised for his interactional 'yarning' approach to therapy and the inclusion of humour in the whole process:

> *He would ... yeah, he would talk to me, you know, sit down and I'd yarn, talk to him and he'd make sure that ... and he was a lovely bloke, and, you know, he had a lot of patience. And he'd look up and he'd start laughing about stuff or something I'd say and that, and ... and he would say, "You're talking good."* (Lorraine, 79 year old, stroke 2 years earlier, living in metropolitan area)

Many of the positive comments were associated with particular individuals that people encountered during their hospital/rehabilitation experiences and the social/emotional support they provided or their ability to provide comprehensible information that people needed.

Inclusion of family. Families reported that they wanted to be more included and informed about their loved one's care. Some participants reported feeling that they were not in a position to request information when it wasn't forthcoming from medical staff. Others simply experienced difficulties in obtaining information:

> *Mother: Well, they should have done something, tell the parent what's going on with their child. We were with our daughter, we knew she got a hiding, but we don't know what treatment she's getting, never know what medication she was on or nothing.*
> *Interviewer: Did you ask?*
> *Mother: No, I never asked. I should have asked really, but they know what they're doing, they should know, you know. They should know that you tell the mother. Yes,*

but they never. I never spoke to the doctor, didn't even know the doctor's name. (Minnie, mother of 44 year old daughter, TBI 22 years earlier, living in rural town, daughter flown to Perth after injury)

Lack of familiarity with hospitals. Explanation of hospital protocols/routines was recommended to ameliorate the lack of familiarity many people feel in the hospital situation:

When you're in the hospital, you know, what the protocols are, "Look, you can't go to the bathroom," you know, "by yourself." ... those messages really need to be communicated to patients properly because ... the patients need to be asked the question "Okay. Do you understand?" ...because otherwise you ... you start doing things yourself, you start going... rogue. They think you're... you're rebellious, or you're not following the rules, where ...you actually haven't been told the rules. You know. Or, you might have and you just didn't ... just didn't register properly. (Brett, 35 year old, stroke 2 years earlier, living in metropolitan area)

One patient had particular difficulty with discharge planning procedures. Her response was:

No, I'm not messing around, I'm going home. If you fellas want me, you know where to find me. They been after me for the two years now. (Danielle, 38 year old, stroke 3 years earlier, living in rural town)

One man described attending an outpatient clinic where signage was poor. The reception staff paid him little attention, he could not find the speech therapy department and ultimately left very disgruntled. He had had numerous unsuccessful interactions although enjoyed the speech

pathologist visiting for rehab in the home. However, overall he reported that he would not go back for further assistance after his poor experiences as an outpatient:

Like I said, been there, done all that. I ain't ... I never go back. [Laughs]. This boomerang don't come back. (Bill, 63 year old, stroke 2 years earlier, living in metropolitan area)

Importance of a single point of contact. Several people emphasised the importance of relationship with one person, a sense of continuity, and the confusion associated with multiple people involved with their care.

If you have a specific person – one at one all the time, not different people. Cos you get used to one person. You know what they're gonna do. You know what they're gonna talk about you know? And how they go with their rehab. (Dan, 42 year old, stroke 11 years earlier, living in metropolitan area)

Health and social contexts

Participants repeatedly brought up their health and social contexts at the time of the brain injury as being of significance in terms of engagement with services.

Comorbidities

Existing comorbidities were common, all adding complexity to medical treatments that typically focus on one system or condition only. One man with aphasia had to go to dialysis

three times/week as well as attend rehabilitation appointments, while another man with aphasia was driving his wife to dialysis. Such situations were not always understood by rehabilitation service providers. Health problems of family members often factored into how the person with the brain injury was able to participate in regular rehabilitation sessions just as much as the individual's own issues. Hence, there was an inevitable inter-linking of the concerns of the person themselves with the health concerns within the family. Awareness and problem solving on the part of the rehabilitation staff was present at least some of the time, with one of the participants reporting that the speech pathologist visited their relative during dialysis sessions as a way to provide the service. However, other people missed rehabilitation sessions as their circumstances were not appreciated or accommodated.

Sometimes, the stroke or TBI occurred just as the participant was dealing with another major health or social issue or both. For example, one participant and her partner recounted that she was preparing for a heart operation when she had the stroke. They were also fostering children at the time. Her partner explained the resultant difficulties:

> *And, yes, a balancing act, you know, you get all this complicated stuff happening in a person's life already and then along comes another complication. We actually had another trauma when the welfare came and took the two boys we were lookin' after – the nephews...... and W couldn't speak and I was just overwhelmed with all this, um, assorted, you know, complications that led to the stroke and dealing with stroke, that we had just no time and, um, the boys are now still in care. So it's like, the system's let us down no matter which way we look ... there's a smorgasbord of, issues, and that's the time they struck. But I still got my wife. (*Clifford, partner of 46 year old person after stroke, stroke one year earlier, living in rural town)*

Common comorbidities e.g. diabetes, kidney disease, heart disease were also sometimes only discovered at the time of the stroke or TBI, often complicating the experience even further for the patient. One patient (previously unaware of other conditions) was admitted for stroke:

I only went in there with a stroke and I come out with all this other shit. But I thanked him for being thorough anyway, because now I know, and I can work with them now to manage it. You know what I mean? (Louis, 64 year old, stroke 6 months earlier, living in rural town)

Social/family concerns

Health and social issues also meant that actions, such as discharging oneself against medical advice, were considered necessities rather than personal choices and not understood by staff within hospital settings. One woman wanted to get home to assist her husband to look after three foster children, when the husband was dealing with mental health problems himself. Another rural participant, keen to get home to family distant from the metropolitan hospital where she was an inpatient, reported her response after being told to relax and focus on her recovery in a rehabilitation hospital:

I can't relax. I've got a two year old baby back there. What do you want done so I can show you and I can get out of here, you know? I'll figure the rest out when I get home. (Danielle, 38 year old, stroke 3 years earlier, living in rural town)

Given the younger age of Aboriginal people having strokes, and the pattern of younger people having TBI, children often factored into participants' stories.

While hospital staff often want to contact family, this is also not always straightforward. For example, when asked about family, one participant described her response to the medical staff:

> *Well, the only one you can talk to is [XX], and she's in XXX prison.* (Dianne, 47 year old, TBI 17 years earlier, living in residential care in metropolitan area but originally from rural area)

There were continuing difficulties for this participant being in contact with any family until much later in her recovery.

Finances

Loss of income occurred for participants who had been unable to work and for carers who had to give up their jobs to look after a family member. This commonly led to financial strain post-injury. Families often had limited finance prior to the brain injury, with extra medical expenses and family relocation costs to allow access to rehabilitation also being a tremendous burden on families. As well as the acute event leading to brain injury, people commented on the expense of attending appointments – particularly follow-up appointments, particularly for people living in a rural area. Participants also highlighted the impact of losing work after brain injury, but also noted the importance of well-timed, financial support.

So I had to stop work. I've been assessed by the Department of Human Services and they've put me on Disability Support... the details of that don't matter, but once I got the card it meant my medications went from a 100 bucks to 18 bucks and shit like that.
(Louis, 64 year old, stroke 6 months earlier, living in rural town)

Recovery and Support

Recovery from the brain injury was discussed from numerous perspectives including attitudes, beliefs and motivators internal to the individual, and facilitators and barriers external to the individual. Internal factors included attitudes/feelings of self-determination and motivations related to family, work, identity, concepts of health, and spiritually motivated beliefs. External facilitators and barriers involved therapy and therapists, family and service supports (represented as outer circles in the model depicted in figure 1). Some participants focused on physical and functional recovery while others focused on longer-term adaptation to disability by making necessary adjustments to their lives and accessing/needing services to support such adaptation. Yet others focused on acceptance and 'getting on with life,' 'living life to the full.' Stories varied depending on the severity and type of disability experienced, as well as ultimate location and living arrangements for example, home, aged care facility, and family context. Some participants had largely recovered from initial disabilities while others had learned/were learning to live with what was a permanent disability – either physical, cognitive, or communication.

Beliefs about disease and recovery/internal motivations

Several participants mentioned recovery in terms of their own resources and determination, and recovery being something that was up to the individual, whereas others mentioned acceptance, 'getting on with life.' The need to be back with and close to family was a major motivation for many people to participate in formal rehabilitation or to engage in self-initiated activities considered important for recovering function, for example, reading, painting, singing, socialising.

> *I had to do it myself. Because I knew basically the only one who could help me to get out of the hospital …which I wasn't happy with because I felt like I was in lockup and I felt so alone, and I cried for visitors. And I knew if I could get myself out of there, um, I could visit the people I love and care about. And that's it. So I did all the hard work for myself to keep on living in this world to be with family and friends and my children. (*Douglas, a 44 year old, traumatic brain injury 11 years earlier, living in rural town)

Return to work also constituted motivation for some. Return to work was associated not only with regaining a regular income, but was closely associated with identity.

Spirituality was mentioned as significant to recovery in terms of both Christian and traditional Aboriginal beliefs. For example, one participant described the relationship of her stroke to her aunty passing away at the same time, and subsequently how she perceived her stroke, having implications for her to recover:

The weirdest thing is, when I got the news, about, ah, my aunty passing away, whilst I was in Port Hedland, at that time, it was weird because, it's like everything had lifted. It was like she took that stroke for me, that pain, and I just ... Aboriginal way, you just feel like that ... That ... that she took it on for me. ... in order for me to live, she died. (Ruby, 48 year old, stroke 12 years earlier, living in regional town)

Others emphasised the importance of God in helping them through recovery, often in encouraging them to be independent, or in feeling "looked after":

I was always thinking about that saying, "God helps those who helps themselves." And I say my prayers to myself and I say at least one Hail Mary, one Our Father you know, in my own way ... to myself. And it's like, I've got to be strong, I got to be strong, I've got to help myself and all this. (Polly, 72 years, stroke 2 years earlier, living in regional town)

External supports

Participants commented on support available at various stages in the recovery, referring mainly to family but also including the support of medical staff and therapists. Information from and access to Aboriginal support groups was also perceived as beneficial:

*It all depends with black fellas whether (you have) good relationship with your family, it's your family. I'm happy with where I am today. I think if stroke victims, no matter who they are, if they have family support I think that they'll always be there and you know that you can trust them and be with them, you know. (*Lorraine, 79 year old, stroke 2 years earlier, living in metropolitan area)

People also commented on the impact of being with others who had experienced brain injury and hearing stories about other people's brain injury either through face-to-face contact or stories included in written publications.

> *…when I had the stroke and I went to XX hospital, I felt it was the end of the earth for me, you know, but when I met other people who are going through the same thing I didn't feel alone, you know. Some people have been in a second time, third time. And here I'm worried about one stroke.*   (Archie, 59 year old, stroke 5 years earlier, living in metropolitan area)

> *And we get newsletters from the Stroke Foundation … reading other people's stories has helped me.*   (Louis, 64 year old, stroke 6 months earlier, living in rural town)

There were some cases where there was an absence of family support, often due to distance or social disruption within the family.

> *…he had … partly stroke and then he just sort of give up because no one was there for him. We used to go and visit him in the hospital but he didn't have that support from his family… he had one son and one daughter and the rest of the family, but he didn't have the support. (*Lorraine, 79 year old, stroke 2 years earlier, living in metropolitan area)

Therapy and therapists played a part for some participants, mainly in the realm of encouragement rather than participants being able to recount specific tasks and activities.

Physical activities like walking tended to be recalled the best. 'Rehabilitation in the home' was identified by several participants as being a beneficial service.

Yeah, and that (rehabilitation service provided in the home) was fantastic. But they only do so many visits. And when I had to go over to the XXX Hospital (as outpatient) and that's when it went pear-shaped. (Archie, 59 year old, stroke 5 years earlier, living in metropolitan area)

There was often a caveat that participants wished the service had gone for longer and were critical of the short length of this service.

An example is when you come home you get … they come and do speech with David….and that was really good and he was moving forward. But it was, like, four weeks and then it stopped. Whether he was ready for it to stop or not. (Jessie, wife of David who had had multiple strokes, living in metropolitan area)

Aboriginal Support / Other Aboriginal people:

Several participants commented on the lack of Aboriginal Liaison Officer (ALO) support in hospital, with most not having seen an ALO during their hospital stay. Some spoke about the importance of opportunities to be with other Aboriginal people after discharge from hospital.

…that's another thing too, like every Thursday when we come together that is a healing there, too, you know. That's, you know. It's like a big corroboree but you enjoy each other's company as well….you know, when you're isolated like this and especially after

a stroke or any event, a heart event or whatever, you know, it's good to get out there

and socialise and have somewhere to go.   (Archie, 59 year old, stroke 5 years earlier,

living in metropolitan area)

Interviewer: If you could go to a nursing home here, where there is a lot of Aboriginal

people, you be happy to stay in Perth?

Participant: Yeah …Aboriginal brothers and sisters. I want to move from here to XX.

Interviewer: Yeah okay, yep. And would that make you feel more comfortable?

Participant: Yeah more comfortable [nods head]. This white man's place. I don't like

white people place.

(Winston, 56 year old, stroke 19 years earlier, living in residential care in

metropolitan area)

Being away from home and family

Many participants were flown to Perth following the injury for both acute and ongoing

rehabilitation care. This meant they were a long way from their country and typically isolated

from family.

I wanted to jump in the car and come back here. Yeah, just homesick.

(Steve, 51 year old, TBI 3 years earlier, rural town - away from home for 2 years after

his TBI)

One participant following TBI was accommodated in a group home thousands of kilometres

from her daughter and family and lost touch with family over a number of years. Another

participant had seven children at the time of her stroke. While her husband attempted to go to

Perth as often as he could, financial constraints and childcare were a significant challenge. One participant emphasised the importance from a more specifically spiritual/cultural perspective of being 'on country' for general healing purposes:

...recovering at home is the best thing one can through with the healing process. [Having a rehab unit closer to home] would be so good, because the mind is important to anybody but for most of countrymen, um, mind's got to be with peace, with your community. (Ruby, 48 year old, stroke 12 years earlier, living in regional town)

Knowledge and beliefs about brain injury (including early reactions)

Familiarity and inevitability

Many participants demonstrated awareness of strokes and their symptoms due to familiarity with family experiences - even to the point of inevitability:

Yeah. I ... I know about strokes from my family having strokes and you know a bit of the symptoms. In the end you learn that ... yeah. Yeah. You learn seeing so many in the family have them, you know the symptoms. (Danielle, 38 year old, stroke 3 years earlier, living in rural town)

So I don't think it was a shock as in ... I think the family history kind of makes it ... you feel it's inevitable really. (Jessie, wife of David – age not given, multiple strokes – last one 12 months prior to interview, living in metropolitan area)

Causality

Knowledge of causality varied from physiological knowledge to attribution to eating certain foods, to spiritual interpretations and the need to be able to discuss the latter in particular without being negated. The participant (Ruby) quoted earlier who attributed her recovery in part to her aunty passing away noted:

> *She died for me to live. I mean, if you told a doctor ... a non-Aboriginal person told this story, ah, you know what I mean, they'd be doubtful, you know what I mean? But, as an Aboriginal person, I know.* (Ruby, 48 year old, stroke 12 years earlier, living in regional town)

Initial reactions

Initial reactions included shock and fear, as well as denial and avoidance.

> *I was in disbelief, because I was too young, I was what, early 30s. It just don't happen to someone like me who walked every day to work, who was fairly physical with stuff in life, and I just can't see ... or, I couldn't understand, why me?* (Ruby, 48 year old, stroke 12 years earlier, living in regional town)

> *But I knew I did because my face was numb, couldn't ... had to, um, um, ... had to, like, use ... make myself use my left side, like, my arms and that. Speech was going a bit funny and I knew I had a stroke. But, I just kept putting it off until ...Oh, I think it was about a week. Like, the next ... the day before I went to the hospital we went in the*

middle of whoop whoop, we went bush dinner out. (Danielle, 38 year old, stroke 3 years earlier, living in rural town)

Follow up

Several people noted the lack of much-needed follow-up after leaving hospital. Some participants reported not being contacted and not knowing who to call. Sometimes outpatient environments were unfamiliar and difficult to navigate, with reception staff unhelpful attitudes also noted as significant. Both metropolitan and rural participants raised the need for assistance in dealing with multiple comorbidities, financial issues and social disruption of various kinds, and ongoing support:

> *"I ... I think you see how we are in the bush, not much services. It would have been good if there was a social worker hooked up to these different services and to help the patient and the family through, like the first six months even, because it's ... that was a difficult time, that you were like, um, you're there, then when you come back out here it became less, and once she came home it was just the odd couple of phone calls, a visit and then you're out there on your own."* (Clifford, partner of 46 year old Theresa, stroke one year earlier, living in rural town)

> *We ran into difficulties. The Aboriginal liaison officers at XX Hospital didn't deal with stroke, they dealt with a specific group that David didn't fit in..... Which is strange because XX Hospital is where the majority of Aboriginal people go* (Jessie, wife of David – age not given, multiple strokes - last one 12 months prior to interview, living in metropolitan area)

People expressed disappointment with follow-up in the community from both hospital and Aboriginal health services and the lack of communication between service providers, particularly in following up on those who had experienced stroke:

*Where I believe, you know, there should be more liaison between our Aboriginal workers, because there's none. I went through my whole period and I didn't see one Aboriginal worker, and that's the truth. I'm not lying. And the only doctor that I could understand was my own old doctor because he ... he was sitting there, he'd say to me, "Tell me what they said? Let me hear what they said." And I ... I would tell him things. And then he'd go and have his say about it, you know. (*Lorraine, 79 year old, stroke 2 years earlier, living in metropolitan area)

Discussion

This study is the first to comprehensively describe the experiences of Aboriginal Australians who have experienced brain injury with resulting acquired communication disorders. Our findings confirm and reinforce themes identified in previous studies describing problems that exist within the health system for Aboriginal people across a range of conditions that are both systemic and relate to apparent unexamined individual racism and stereotyping [40, 41, 42, 43]. However, our findings also document stories of independence, strength and determination to get on with life.

Of additional significance is the way in which communication difficulties, intrinsic to the clinical condition, interact with the other challenges that are well described in studies dealing

with other conditions. The fact that people are dealing with a sudden, life-changing event often accompanied by changes to communication and cognitive skills adds complexity to an already-difficult context. These changes can seemingly alter the person's identity overnight and further interfere with both immediate and longer term health service provider interactions. The changes can complicate family relationships through a sudden change in roles, financial difficulties and inability to clearly communicate needs and reactions, particularly in the initial acute stages. And families are often not equipped to deal with loss of communication with their loved ones or to facilitate ways of enabling their voices to still be heard. Co-morbidities in the brain injured patients and health needs of others in the family place additional stress, often with extreme challenges in taking care of children and other dependents. Strong themes emerged concerning the need to be near family and on-country. This need often drove people away from hospital/specialist/follow-up services to return home. Information overload, varying beliefs about the causes of their condition and inadequate and inappropriate follow-up services meant that culturally safe opportunities for rehabilitation were few. While some of these issues also apply to non-Aboriginal patients, the challenges are amplified by the additional cultural, clinical and logistic complexity experienced by many Aboriginal patients.

The discussion below relates to the 'individual' themes identified but also attempts to reflect the integral interaction of the themes as related to the socioecological model depicted in figure 1. These factors merge to shape the recovery journey of the person with a brain injury.

Communication

Recommendations to provide information to patients and families related to long term management rather than restrict information largely to medication and medical appointments after discharge clearly point to individuals' needs for practical support following brain injury.

This finding has been highlighted repeatedly in the brain injury literature to date but the information has obviously not been made accessible to all people who have survived the brain injury. While much has been written about this and educational brochures, DVDs and other materials developed for the broader brain injury population [44], there is clearly more work to be done in producing materials that are relevant to Aboriginal people. However, beyond written/visual materials that may be useful for some people [45], interactional notions of health literacy obviously need to be discussed. Rather than seeing health literacy as a 'knowledge' or 'skill' residing within the patient, health service providers must increasingly acknowledge their role in producing and conveying information to patients in a way that is culturally appropriate and accessible.

While individual hospital experiences of participants in this study varied, the impact of overarching systemic issues was clear and familiar – miscommunication, lack of practical information, and families feeling excluded. Cultural brokerage - enabling "clearer communication of cultural specific needs to health professionals who then facilitate more holistic care" [46] (p.6) and involving "two way communication where both parties are informed and equally important in the discussion" [47] (p. 23) – was mostly not available, with limited involvement of ALOs. Given that recovering from brain injury may present even more and different challenges for Aboriginal people than recovering/living with other illnesses, cultural brokerage would seem a fundamental requirement of appropriate and culturally secure rehabilitation [48].

The person's ability to assert themselves (often already constrained by white privilege embedded in the society and its institutions) is further compromised by communication and/or cognitive disorder. While the need for Aboriginal health staff has been repeatedly

recommended for general hospital care [43, 49], the number of Aboriginal Liaison Officers in hospitals remains notoriously low. Staff are often deployed in emergency situations affecting family, or towards related to patients with chronic conditions such as diabetes, kidney failure, and heart disease rather than those related to brain injury. There didn't appear to be a difference in this regard between those interviewed many years post injury compared to more recently discharged participants.

Participants relayed positive experiences with health professionals who took time to sit down with them and engage in two way interactions. Health professionals who explained the nature of their illness in everyday terms and ways to move forward on a practical level were regarded positively. Health professionals who 'listened,' who engaged in more casual interactions using humour and 'yarning' techniques, were also positively regarded. Having an ongoing relationship with one therapist or practitioner was regarded as important in providing some degree of familiarity and predictability of what might happen next.

Recommendations emanating from both the positive and negative experiences of participants inform the contents of table 4. Many of these recommendations are relevant not only in care of people with ACD but in the care of all Aboriginal people with brain injury, as well as services related to a number of health conditions.

Insert table 4 here

Health and social contexts

The need for health professionals to be aware of the social context of their patients and to develop strategies to deal with these was clear. While some people with brain injury may have

strong supportive families in close proximity, others might be away from family for a variety of reasons. Hence the need to provide the best information for either the patient or support person is critical. Financial, family and cultural commitments may make it difficult for family members to accompany their relatives from a regional or remote area to a hospital facility in a larger city. The middle class, predominantly white metropolitan health workforce often has little personal knowledge or experience with what some of these kinds of issues might entail. The interaction between the societal attitudes and worldview, the family of the person with the brain injury and their community context, and health services offered (see figure 1) is central to understanding the context. In the biomedical model, a social worker will be allocated to help the person deal with 'social problems' or 'financial problems' post brain injury. This approach demonstrates the 'silo' approach of the biomedical model of health which tends to deal with life issues individually rather than as interrelated components of an individual's context. The services offered in this model do not typically align with an Aboriginal view of health, hence may not meet the needs of the individual and may present another layer of barriers to recovery in terms of navigation of multiple services. Rather, all health professionals involved with the person need to be sensitive to the person's holistic context if they are to provide effective support to that person.

Recovery and support

Many individuals in this study wanted more rehabilitation treatment, support and information, even when facing multiple comorbidities. This finding was contrary to some health professionals' assumptions in the broader Missing Voices project [50]. Several participants emphasised a preference for seeing one person in the hospital (as noted above) who could explain everything to them, rather than so many different people. There was a keenness to find

out information and make decisions but only if enabled through a more holistic and streamlined system.

Previous research has shown that health practitioners often express the sentiment that Aboriginal patients do not always 'prioritise' their stroke rehabilitation because of having to deal with other illnesses [50]. The interviews suggest that the notion of 'prioritising' one illness/treatment over another may not necessarily represent reality for Aboriginal people after brain injury. It more likely reflects the biomedical model of health which deals with body parts or systems and rarely addresses illnesses holistically. It also reflects a lack of awareness of the multiple demands and complex contexts in which many Aboriginal people live. Navigating multiple health service appointments makes attending to the complexity of conditions in the family concurrently impossible, even though issues such as speech and mobility actually may be high on a person's 'priority' list. The interviews did not appear to reflect a 'prioritisation' process occurring.

Clearly, Aboriginal support was wanted by many participants. This reflects the need for more Aboriginal health worker support both in hospitals and in Aboriginal community controlled health services, where contact tended to be incidental rather than systematic, with more of an existing focus on traditionally defined 'chronic diseases.'

Rehabilitation services are often reported to be non-existent in many regional and rural areas, and brain injury, whilst a chronic condition, often does not fit into the chronic disease categories to which health resources are targeted. Because of the nature of brain injury, the person with the brain injury (and their family) ends up navigating the system from a point of disadvantage (from an 'accessing service' perspective at least), attempting to deal with the

personal effects of the brain injury (e.g. change of identity, disempowerment due to communication and cognitive difficulties, shock, looking for explanations – physically and/or spiritually based), as well as the effects on the family including emotional and financial consequences. Such navigation often occurs away from country and family, creating further emotional and/or spiritual challenges. Kelly et al's documentation of Aboriginal patients' journeys for treatment off country, and possible tools for rehabilitation health professionals to use when mapping and facilitating these journeys are examples of possible ways forward to assist in this complex navigational context [51, 52].

Being away from home and family

As just noted, being away from country and family, as is often the case in brain injury, presents numerous challenges that must be taken into account in rehabilitation plans. Currently developing telehealth service delivery in brain injury rehabilitation promises significant potential opportunities for improving outcomes in this regard. People may now be able to return home sooner and receive rehabilitation through telehealth, or they at least may be able to be in contact with family on country when hospitalised in the city for either acute care or rehabilitation [53, 54].

Knowledge and beliefs about brain injury

The familiarity with, and for some participants, the perceived inevitability of stroke in particular, was striking. Many people had family members who had had a stroke at a relatively young age and were familiar with symptoms. However, there was little knowledge of rehabilitation processes or the implications of neuroplasticity for recovery. Feelings of simply getting on with life using your own resources were the most commonly reported reactions to recovery, and were consistent with our previous pilot study [6]. This familiarity with stroke and brain injury aligns with the high level of comorbidities in Aboriginal people

[55], an overall increased familiarity with illness and death as compared to non-Aboriginal people, and frequently an apparent resignation to illness occurring at a young age. Again, an understanding of this context is essential for health professionals working within the realms of this experience.

Follow up

Stroke is often overlooked as a chronic disease even though effects are typically long-term. Mapping tools of recovery journeys for other diseases are emerging [51] which may assist in facilitating services for people with brain injury as well. However, the current study suggests that follow up after brain injury remains limited. Due to a combination of the factors noted above, there is much work to be done in ensuring that Aboriginal people post brain injury are able to access supports post discharge from hospital, and that active and culturally secure follow up systems are in place that ensure ongoing accessability.

Importance of cultural identity

The participants raised numerous points that they perceived as beneficial to the person's recovery – not surprisingly almost always related to communication and social interaction, but also related to location. The benefits of hearing 'language' (be it your own or even another Aboriginal language), being around other Aboriginal people, having strong family connections, a strong sense of internal determination and an attitude of 'getting on with life' resonated throughout the interviews, contributing to a sense of cultural identity being a much perceived source of strength. Reference to one's country being central to healing reiterated this sense. Change in identity after brain injury is written about extensively in relation to aphasia affecting interpersonal relationships, sense of self, employment etc [56, 57]. However, this research emphasised aspects that related to maintaining a broader cultural identity and this perspective appears to be new in the brain injury field to date. For example, while social interaction after

brain injury is typically considered beneficial from both an interpersonal and neuroplasticity perspective [58, 59, 60], the somewhat deeper emphasis on the benefits of being with family, being with other Aboriginal people, and hearing language in the Aboriginal context, potentially speaks to the strong inter-relationship between cultural identity and health [61]. This is often discussed in relation to Aboriginal health, with language in particular being central to cultural identity.

Hence, while the dominant culture context affected many interactions negatively, the strong cultural needs and strengths of the people after brain injury and their families provided a positive impact on recovery. Regardless of their residential location, participants who were living at home, in hostels and aged care facilities at the time of the interviews reported a better sense of wellbeing when surrounded by other Aboriginal people, when their family was close (or visited regularly), and when they were able to either simply hear Aboriginal language or engage in yarning in their own language. The reports of increased responsiveness and animation, particularly in those with severe communication disorders, speaks to the power of language in this sense.

The model in figure 1 illustrates how communication crosses all the levels of context, and is impacted through each level. Each context represented by each concentric circle provides another layer of communication, all being impacted by the western medical system and society which are the formal providers of care for the individual with a brain injury. At the service level, service providers (nurses, doctors, therapists) primarily represent the non-Aboriginal knowledges and values that are part of this system. Situated within this is the Aboriginal family who provides the ongoing individual care yet is dealing with medical trauma in a health context that is typically different from their own cultural constructions of health and wellbeing. While

some of the stories reported are similar to what has been reported in other studies, and indeed in the general community, it was the 'sub-themes' and related themes which further revealed differences in the Aboriginal person's journey as both s/he and their family attempted to navigate a system dominated by western medical frameworks and white privilege [41]. As each circle within the model impacts both the inner and outer circles around it, so is the context for the Aboriginal person with the brain injury and health provider realized. The influences are two way, hence two way solutions are required if the issues raised by the participants in this study are to be addressed. Each of the themes emanate from a combination of the influences depicted by the concentric circles of the model. Addressing one of these without understanding the overarching context can continue a silo-ed 'bandaid approach' to improving health services and patient outcomes. With this in mind, communication recommendations based on the themes and embedded in the interviews are depicted in table 4.

Conclusion

Brain injury is a sudden occurrence where life can change overnight and yet the consequences persist long term, requiring ongoing, multidisciplinary input. Unlike other conditions where medical treatments are used to keep the condition in check (e.g. diabetic and cardiac medications), long-term brain injury rehabilitation and recovery typically involves cognitive and behavioural interventions and practices. In addition, families require practical strategies and information to assist with long-term life adjustments to issues such as employment, physical care, access to social networks, and dealing with behaviour and personality changes, as well as assistance in dealing with deeper identity changes and family disruptions associated with long-term disability.

The stories contained in this paper point to ongoing need to further increase the largely non-Aboriginal health service providers' appreciation of the health and social contexts of Aboriginal people with brain injury in order to be able to offer accessible services. The experience of the person and family in the acute stages can significantly influence what happens in the longer term in terms of using available services and re-engagement with community. Ongoing support is required for this typically chronic condition where both symptoms and context can change over time – sometimes improving, sometimes getting worse. Good communication and contact with health service providers at the outset is crucial to establishing the ongoing links and resources often needed. The focus on communication in this paper and others in the field of Aboriginal health suggest that required changes often surround interactions and 'how business is done' in the health field, rather than the need for increased monetary resources.

An overwhelming reference to the importance of cultural identity in relation to recovery is one of the important findings of this research. This differs from previous research into ACD which has focused on identity change related to the individual only. Most likely this can also be applied to Aboriginal people who have had a brain injury beyond those with ACD alone. A strengths-oriented perspective suggests focusing on acknowledging cultural identity as key to ensuring cultural security and ultimately recovery. It goes beyond the Western construct of 'disability' which is typically 'impairment' focused, and acknowledges that recovery is related to factors well beyond medical 'treatments' of that impairment. In this context, facilitating recovery goes beyond supplying Western therapies e.g. physiotherapy, speech therapy, and simply 'ensuring cultural security' whilst in hospital. This perspective speaks to the necessity of ensuring an environment in which Aboriginal people after brain injury are in the best

position to utilise their cultural resources through involvement of family, involvement of other

Aboriginal people in recovery processes, access to language and proximity to country.

Declaration of Interest

The authors report no conflicts of interest.

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Table 1. Participant with ACD characteristics

Age range	Injury	Time post injury	Sex	Language group	Living arrangements
35-79 years	Stroke = 23 TBI = 6 Stroke+TBI = 3	8 mths-33 years	**Stroke** Male = 13 Female = 10 **TBI** Male = 5 Female = 1 **Stroke + TBI** Male = 1 Female = 2	Arrente Djiban Noongar Nyul Nyul Ngangumarta Wongi Wongatha Yawuru Wajarri	Home = 19 Residential care=13

Table 2. Family/carer characteristics

Sex	Relationship to person with ACD
Female =13 Male =3	Spouse = 8 Other family member = 2 Friend = 1 Paid carer =5

Table 3. Themes and sub-themes emerging from the interviews

Communication		Health & Social Contexts	Recovery & Support	Being away from family & country	Knowledge & beliefs about brain injury	Follow up
Communication specifically related to ACD	**General communication issues**	• Comorbidities - Diabetes - Heart conditions - Hypertension - Kidney failure • Social/family concerns - Family members' health conditions - Caring for children/foster children - • Finances	•Recovery up to yourself/internal motivations - Family - Work - Identity - Spirituality •External supports - Family - Therapists - Other people with brain injury •Aboriginal support	• Transfer from rural to metro for treatment causing disruptions to - family life -finances • Importance of country to healing process	•Familiarity with stroke and TBI •Inevitability •Causality •Initial reactions - denial - fear	• Lack of follow up post hospital discharge • Need for Aboriginal Liaison Officer support post hospital discharge • Need for practical information
•Anger, frustration & powerlessness •Change in identity •Mis-diagnosis •Importance of language •Stereotyping	•Medical jargon & information overload •Type of information needed •Yarning, humour and support •Inclusion of family •Lack of familiarity with hospitals Importance of single point of contact					

Table 4. General Communication recommendations

- De-'medicalise' and avoid jargon within information given by health providers to Aboriginal people after brain injury so that communication is clear and terminology easily able to be understood, with time given and sufficient respect demonstrated for the patient and family to ask questions and ask for clarification ;

- Ensure information is provided to patients and families that relate to longer-term expectations and strategies for management of brain injury sequelae such as behavioural/personality changes rather than focusing only on immediate medical concerns (medications, future appointments);

- Ensure Aboriginal Liaison Officer assistance is enlisted early on whilst in hospital to facilitate communication or support;

- Ensure staff are aware of different Aboriginal languages, have access to information that enables them to identify the language of all patients (utilising the knowledge and skills of the ALO if possible), and to enlist the assistance of appropriate interpreters;

- Acknowledge cultural sensitivities and processes in order to align with cultural expectations of patient e.g. families sometimes expected to look after intimate bodily functions of family member; age and gender issues sometimes raised);

- Include families in conversations about their family member, ensuring two-way communication is occurring;

- Ensure clear communication and explanation of hospital 'rules' by staff rather than expecting patients to be aware of these, providing flexibility to acknowledge cultural difference and expectations ;

- Ensure opportunities for yarning (social, diagnostic, and management) in order to engage with patients, including humour and generally supportive conversation techniques particularly for those with cognitive and/or communication problems;

- Have one key person for the person with brain injury and family to relate to (who works closely with the ALO) in order to develop a consistent, trusting relationship;

- Train staff in cultural security, particularly in relation to interactions and working with patients unfamiliar with a hospital environment;

- Include an orientation to the hospital or rehabilitation environment, improve hospital signage regarding service locations and directions, and give consideration to the importance of the environment as welcoming for Aboriginal patients and families.

Figure 1. The positioning of the Aboriginal person after brain injury within a service, family/community and wider societal context [37].

Society and institutional systems

Family and environment

Rehabilitation service provision/interaction

Aboriginal person with brain injury