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Article *in* International Journal of Speech-Language Pathology · April 2012

Impact Factor: 1.24 · DOI: 10.3109/17549507.2011.663790 · Source: PubMed

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International Journal of Speech-Language Pathology, 2012; 14(3): 271–280

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healthcare

Living with aphasia: Three Indigenous Australian stories

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The incidence of cardiovascular disorders and stroke in Australian Aboriginal communities is more than twice as high as non-Indigenous Australians. Approximately 30% of people who survive stroke are left with some level of aphasia, and yet Indigenous Australians appear to be infrequent users of speech-language pathology services, and there is virtually no research literature about the experiences of aphasia for this group of people. This paper presents the stories of living with aphasia for three Indigenous Australian men living in Perth, Western Australia. Their narratives were collected by an Indigenous researcher through in-depth, supported interviews, and were explored using both within-case and cross-case analyses for common and recurring themes. It is argued that there is value for speech-language pathologists, and other health professionals, to be aware of the broad experiences of living with aphasia for Indigenous Australians because their stories are rarely heard and because, as with people with aphasia generally, they are at risk of social isolation and tend to lack visibility in the community. This study explores the key issues which emerge for these three men and highlights the need for further research in this area.

Keywords: *Indigenous Australians, aphasia, qualitative interviewing.*

Introduction

Despite the high incidence of stroke in Indigenous Australians (Australian Institute of Health and Welfare–AIHW, 2011a), there is virtually no research literature about aphasia in this population to date. People from Aboriginal and Torres Strait Islander backgrounds constitute ~ 2.5% of the total Australian population, and this proportion is growing (Australian Institute of Health and Welfare–AIHW, 2011b). There is one mention of an Aboriginal man with a global aphasia in an article by Faux, Ahmat, Bailey, Kesper, Crotty, Pollack, et al. (2009). This man was a 68-year-old Yolngu Aboriginal Elder from East Arnhem Land who spoke limited English. Despite his niece acting as escort, and access to an Aboriginal Liaison Officer, his severe aphasia, combined with the lack of adequate interpreting services, caused him and the hospital staff significant difficulties both with his management and discharge arrangements. Another study undertaken in 2004 by the National Stroke Foundation reported on stroke stories from 16 Aboriginal people in the Geraldton, Midwest, and Pilbara regions of Western Australia addressing attitudes and issues related to stroke, and mentions speech difficulties, but does not specifically explore this issue.

This situation is reflected in the general lack of literature on aphasia in Indigenous peoples throughout the world. While issues are being raised in terms of communication disorders in these populations (see special issue devoted to this topic in *Clinical Linguistics and Phonetics*, 2008, volume 22 (8)), studies have predominantly focused to date on the paediatric sphere, or have focused on general issues of service delivery (e.g., Cass, Lowell, Christie, Snelling, Flack, Marranganyin, et al., 2002; Harwood, 2010). In a review of the literature exploring the Maori experience of aphasia in New Zealand, McLellan, McCann, and Worrall (2011) reported finding no specific articles on this topic using the major databases. They found four articles that were related to outcomes after stroke or conditions related to communication disorders in this population; however, Maori participants constituted only a small part of a larger study looking at these issues in the wider New Zealand population, and the study did not specifically refer to aphasia. A review of literature undertaken by the authors in regard to Native Americans revealed two case studies of people with aphasia (Huttlinger & Tanner, 1994; Hickok, 1996), while the Canadian literature revealed one paper

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ISSN 1754-9507 print/ISSN 1754-9515 online
Published by Informa UK, Ltd.
DOI: 10.3109/17549507.2011.663790

addressing clinical interaction issues when working with individuals from First Nations backgrounds (Simmons & Small, 2010).

In terms of the Australian context, the lack of literature is unhelpful considering the need to address the gap in health outcomes between Indigenous and non-Indigenous Australians with aphasia. While there are limited statistics on stroke in Indigenous Australians, both incidence and mortality rates are known to be at least more than twice as high as for non-Indigenous Australians (AIHW, 2011a; Katzenellenbogen, Vos, Somerford, Begg, Semmens, & Coddie, 2010; Thrift, Cadilhac, & Eades, 2011), and Aboriginal and Torres Strait Islanders are known to experience stroke at a younger age than their non-Indigenous counterparts (AIHW, 2004). Additionally, when considering managing disability in the longer-term after such events as stroke, the AIHW (2008) reports that Indigenous Australians are more likely than non-Indigenous Australians to be caring for a relative with a chronic disability, long-term illness, or problems related to old age.

Given these statistics, and the fact that the wider aphasia literature reports that ~30% of people having strokes are aphasic (Engelter, Gostynski, Papa, Frei, Born, Ajdacic-Gross, et al., 2006), it could be presumed that the number of Aboriginal people with aphasia is significant and that their needs are well recognized. However, Aboriginal and Torres Strait Islander populations do not typically utilize speech-language pathology services and, for a range of reasons, may have other priorities (Edis, 2002). These include issues related to other major health problems such as diabetes, renal, and heart failure, social issues such as those related to housing and family dysfunction, and cultural commitments such as attendance at funerals or other traditional ceremonies which can involve extended periods of time. In addition, the fact that 145 different Aboriginal languages are still spoken within Australia according to the National Indigenous Language Survey (Department of Communications, Information, Technology and the Arts, 2005) makes it likely that access to services may be restricted in some areas due to lack of appropriate interpreting provision. Anecdotally, speech-language pathologists see Indigenous people in hospital after their stroke (if they are admitted to hospital), but rarely have ongoing contact in the longer-term. This situation appears consistent with a statement made in a discussion paper of the New South Wales Aboriginal Disability Network (2004/2005, p. 11) *Telling it like it is*, which suggests that Indigenous people with chronic disability may become marginalized: "The lack of visibility of Aboriginal people with disability within some communities means that they can literally be at the margins within their communities and the wider community".

A number of researchers, such as Ariotti (1999, p. 221), have explored Aboriginal constructions of disability and suggested that "service provision … must be based on scrupulous attention to the way each individual and community defines disability". He suggests that disability, specifically in Anangu culture, in the cross-border region between Western Australia, South Australia, and Northern Territory, is a dynamic construct closely connected to the local history, culture, and language. Similarly, Boddington and Räisänen (2009), while recognizing the diversity within Australian Aboriginal conceptualizations of health, highlight the holism inherent within such conceptualizations. They suggest that Aboriginal notions of health go beyond even the broad biopsychosocial model of the World Health Organization—the *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001, p. 57) by including cultural aspects: "… several aspects are incorporated into the definition of health, notably reference to the whole of the life course, self-determination, community and culture as well as dignity and justice". Interestingly, within the field of aphasiology, such views fit well with social approaches which emphasize addressing aphasia through genuine partnership, empowering people and working with family and community in authentic contexts and services (Byng & Duchan, 2005). Moreover, listening to the experiences and stories of people with disabilities is an important way of bridging cultures as well as developing holistic and relevant treatment approaches. Hinckley (2008, p. 129) suggests that

> a narrative-based approach emphasizes such a holistic view by acknowledging global concepts like identity. The personal, social, and cultural milieu of the person living with a communication disorder should play a powerful part in the research and clinical agenda of speech-language pathologists.

For these reasons, we felt that a useful step towards understanding the stroke and aphasia experiences of Indigenous people was to listen to their stories. We wanted to find out how aphasia was constructed and dealt with in Aboriginal communities and try to understand more about how Aboriginal people adjusted to aphasia in the long-term, often beyond the usual speech-language pathology services. With funding from the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), we initiated a pilot study which aimed to explore the experiences of 10 Aboriginal people who had aphasia as a result of stroke, and their families, within the Perth metropolitan area. We were interested in Indigenous cultural attitudes to aphasia in adults after stroke, the functional and personal consequences of aphasia, experiences of services received after the stroke, and stories of living with aphasia. This paper reports on the stories of just three of those participants, because we felt it was important to focus on their experiences in some detail. These three men have some things in common, but also represent different severities of aphasia, and different times post-onset.

Method

We worked with a reference group of Indigenous health workers and people involved in health and support agencies in the local community. This group was an important source of information on culturally appropriate research and was consulted on a regular basis, particularly during the initial stages of the project. Ethics clearance for the study was gained through the University, the local hospitals, and the Western Australian Aboriginal Health Information and Ethics Committee.

Potential participants for the larger study of 10 Indigenous people were recruited through speech-language pathology hospital departments and community referral in the Perth metropolitan area. Recruitment was initially slow and it appeared at first as if Aboriginal people with aphasia did not exist. When talking with Aboriginal Health Workers, few initially identified people they knew with stroke, and even fewer with communication problems. Speech-language pathologists reported seeing very few Aboriginal clients, and there appeared to be few if any Aboriginal people in the local stroke support groups. In addition, the following difficulties were encountered with hospital referrals:

1) People who had been seen in Perth hospitals had often self-discharged against medical advice and had not returned to the hospitals for rehabilitation. They were not always easy to contact, perhaps because they had moved house, because their phone numbers were no longer active, or simply that telephone calls were not answered or returned;
2) Many patients on record in Perth hospitals were from rural areas and had returned to rural areas after discharge from hospital in Perth;
3) The majority of Indigenous people who were seen by speech-language pathologists after their stroke in Perth hospitals were recorded as having swallowing difficulties rather than communication problems; and
4) Some patients had such severe concomitant medical problems that they were not considered suitable for the project at that time.

Nevertheless, despite these initial difficulties, recruitment gradually occurred—predominantly through snowball sampling (Morse & Field, 1995), and was facilitated by personal contacts of both the research assistant and the reference group.

Participants

The three participants, Deryck, Simon, and Andrew (pseudonyms), were accessed through the above means within the Perth metropolitan area and were a minimum of 3-months post-stroke, with a diagnosis of aphasia. We focused on the metropolitan area only for this initial study, as resources were limited. However, future studies will explore the experience of individuals from rural areas, as certainly many of the people in Perth hospitals were from rural areas and were referred back to these areas. Participants also included family members where possible. All were speakers of Aboriginal English. Additional details about each participant are found in the Results section.

Data collection

The three participants described in this paper took part in semi-structured interviews based on questions exploring barriers and facilitators encountered, experiences of communication difficulty in everyday life, attitudes of others toward communication difficulty, hospital experiences, and experiences of speech-language pathology. No formal language assessments were administered. The interviews were primarily carried out by an Indigenous interviewer and took place in the person's home, although, for one man, two repeat interviews were undertaken at the university where two of the co-investigators took part. Two of the three men were interviewed with a family member present, in both cases a sister. The participants were asked if they preferred separate interviews for the person with aphasia and for their family member or whether they should be interviewed together, and both said they preferred the latter. We report on both perspectives in this paper. The third participant had no family close by and wanted to participate alone.

The interviewer was a Yamatji woman with enrolled nursing experience, as well as experience in conducting health-related questionnaires and interviews for research and clinical purposes. She lived in Perth and had strong involvement within the Aboriginal community. Yamatji people are from the Murchison and Gascoyne regions of Western Australia. As part of the general introductions prior to the "formal" interview, the interviewer discussed her family background and in fact she knew two of the participants prior to this. The interviewer reported that the different language group backgrounds in the study between the interviewer and some of the participants did not appear to be problematic in the negotiation of the interview. For those participants referred from Perth hospitals, basic medical information about the time and type of stroke, and any associated impairments were accessed through the referring speech-language pathologist. In preparation for the interviews in this study, the researchers provided the interviewer with education about aphasia and training on the most effective ways of communicating with people with aphasia based on principles of Supported Conversation (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001).

Data analysis

The interviews were audiotaped and transcribed. The transcribed data was then coded for themes (Sandelowski, 2000; Taylor & Bogdan, 1994) initially within each case and later across the cases (Cresswell, 2007). The analysis was driven by both intrinsic and instrumental interest in the cases (Stake, 2005, p. 445) in that the individual stories and experiences were very important, but each case also provided insight into the overall issue of experience of aphasia for Indigenous people. Stake (2005) calls this dual view "a zone of combined purpose". As part of ongoing analysis, the interviewer returned to participants where possible so, with two of the three participants, there were follow-up interviews to validate, clarify, and expand on data. The analysis was a shared process with detailed discussion around coding and checking back with participants and family members.

Results

In this section, we present three stories: Deryck, Simon, and Andrew.

Deryck

Deryck is a 63-year-old Noongar man (Noongar people are from the south-west corner of Western Australia from the land stretching from Geraldton on the west coast to Esperance on the south coast). He had his stroke when he was 34-years-old, 29 years previously. His verbal output was characteristic of Broca's aphasia, although he also demonstrated a moderate comprehension deficit. He had a right hemiparesis, little use of his right arm, but was able to walk independently with a stick. His other known and ongoing health issues were high blood pressure and diabetes. Deryck lived with his sister. The Indigenous interviewer initially spoke with Deryck and his sister together, and he subsequently agreed to see the researchers on two other occasions.

Deryck grew up in a rural area of WA and was employed as a cattle musterer. It is unclear exactly when he moved to Perth. Deryck liked to introduce himself as a singer and a painter. He played guitar and sang Country and Western music in a band prior to his stroke, but now sings karaoke at a local pub on particular nights where up to 200 Aboriginal people often attend. While his report of this was not clear, Deryck said that he liked to meet friends there. He became very animated when talking about the karaoke nights. He reported that, prior to his stroke he was a heavy drinker, but that he has not used alcohol for many years. Deryck was proud of his painting (landscapes and people) and currently has a painting hanging in a major gallery in Western Australia. With his permission, we have included an example of his work in Figure 1. Deryck reported attending a community centre each week, as well as an art class conducted by DADAA (Disability in the Arts/Disadvantage in the Arts Western Australia). He also reported travelling around Perth to galleries, and simply to meet people. He catches the train independently and also uses taxis, although his sister reported that people were not always patient with him on public transport, particularly in relation to his hemiparesis slowing him down when getting on and off buses. He was known to the interviewer (JF) who often saw him in coffee shops locally, and talking to people in the street. Deryck spent most of his time out and about independently, but also spent time with extended family. While his speech was limited, he communicated quite well, and was able to ask for what he needed and to direct people around him, including inviting the researchers to the karaoke, and to an art exhibition to see one of his pictures. However, Deryck's sister reported that she had to manage many everyday aspects of his life, including his diabetes medication, his taxi vouchers, laundry, etc.

When asked about his aphasia, Deryck did not appear to be concerned. He dismissed most questions about this, denying any difficulties, and was much more interested in discussing his art. He had no complaints about his hospital experiences. When asked specifically if his speech affected him he said "good 2026 better", indicating that it had improved over the years. He experienced word-finding difficulties during the interviews, but often persisted until he found the right word. Deryck's sister reported that he was integrated into family

Figure 1. Deryck's drawing of his home country.

activities in the same way as other family members, but that there were sources of frustration:

> … they um are remorse for him but sometimes they get agitated with him 'cos sometimes he ah can't think of some certain things that he's supposed to explain to you like people he's seen and them forget that Deryck got a stroke and tell them to pass the message onto the sisters and he's sayin' "um um that person" he can't remember the name, you know, and the sisters get agitated and say "which person?" you know, so he lose the memory of who he's talkin' to sometimes …

She also felt that he should have some ongoing service assisting him with everyday living. While they made use of a community service which provided home care, she felt he needed more than this because of his diabetes and blood pressure rather than his speech problems—more monitoring of his health status:

> because he had more major issues than havin' the strokes. I mean high sugar diabetes.

While Deryck had obvious health issues, and was clearly dependent on his sister for many of his self-care needs, he was busy and connected to a range of people, and social and recreational services. His aphasia did not feature as prominent in his interviews at all. He appeared to have found his expression through his karaoke and his art. His paintings were often about the place he came from or possibly the people he knew when he was younger. Deryck was an example of a man, many years post-onset, who was "living successfully" with his aphasia (Brown, Worrall, Davidson, & Howe, 2010)—or perhaps even without it, considering its absence from his story. He showed no evidence of missing fluent speech, or of being particularly concerned about it. Any mention of frustration related to word-finding problems or communication breakdown were from his sister rather than him.

Simon

Simon was a 53-year-old Yamatji man who had his stroke 6 months prior to the interview. He had a moderately severe aphasia initially that resolved relatively quickly so, by the time of his interview, his language skills were good. He had three children, was living with his auntie prior to the stroke, but was currently living with his sister. He had a history of heart failure and had not worked for many years prior to the stroke. He reported having used alcohol heavily in the past, but had since stopped drinking because of his health.

Overall, both Simon and his sister reported being very satisfied with their hospital experience. He said "I enjoyed it there 'cos I was, I knew I was getting looked after …". When asked what was most helpful for him during this time in hospital, he emphasized the importance of knowing people there, not feeling isolated or the only one with a problem:

> The feeling of just goin' down and talkin' to a lot of people. Like I seen a lot of people that I know in hospital. Would go for a walk with them talking. Some people was the same thing like I was y'know …

Simon met people in a "meeting area" just outside the hospital. His family (sister and one son in particular) came to the hospital—often till late at night when he sometimes had to ask them to leave as he was too tired for visitors. His auntie came once but became too upset, and his sister said that she wasn't allowed to re-visit as the family felt he did not need someone crying by his bedside. They felt it was more important to be positive with him. One son would not visit the hospital—he has similar heart problems—possibly not wanting to face something that could also happen to him. Simon mentioned other hospital incidents such as helping another patient who suffered from heart problems to find a comfortable position—he felt able to advise because of his own previous experience with heart issues. He recounted times when his family took him outside the hospital in a wheelchair and laughed at one incident when he was wheeled "enthusiastically" down the road.

When asked about speech-language pathology services, Simon said he could remember someone leaving a booklet. However, primarily, he reported feeling frustrated by his difficulties, by his failures, and with some of the therapy activities he was asked to do whilst in hospital:

> Oh they come down and spoke to me for a little while there … some spelling and writing down words … Some parts I couldn't, got really hard that I couldn't do … Couldn't work it out so I just stopped doin' it like … So that was too frustrating … you feel … yeah, you're so useless an' that … like little kids an' that do there, you know? I knew it wasn't sorta like that. I knew what I was doing. But see, I'm a strong sorta person, you know, that's my life. I sorta found it a bit hard to do simple things that I couldn't do y'know? And it was getting on my nerves.

Simon's comment about feeling "useless" was highly significant. When discussing his initial reaction to the stroke, Simon reported feeling suicidal, but his thoughts were tempered by the importance of his family and feeling that they needed him:

> I thought about many times I thought about committing suicide eh … I was thinkin' about doin' that … 'Cos I just (—) it … So I thought uh my family's too (—) so I'll just work on that, work at it, work at it.

Simon said that, as a result of not drinking now, he doesn't have many friends, but walks his dogs to the local park where he meets friends to talk. He also accompanies his sister to her work at times, but, due to health reasons, cannot do a lot physically. He appeared very concerned about his current health and medication to control his blood clotting. His sister was very focused on keeping his diet healthy. She also stressed that they used humour to help cope with the stresses of his ill-health. Simon compared himself to friends who also had severe health problems—one friend had had a stroke and was now in a wheelchair:

> There's worse than you, you know like. People are so unfortunate, you know.

A key theme running through Simon's interview was that he could do things by himself, including directing his own recovery from his communication problems. He reported reading the paper each day as being significant in helping his language. When he went home, he said he talked to his dogs and his birds as practice for his speech. He went for one outpatient appointment with a speech-language pathologist but said that what they got him to do was too difficult and he felt he could help himself more effectively:

> thought it wasn't right for me cos I knew what I could do an' that. It was just my speech that I couldn't sorta couldn't do anyhow and I thought well ... I could do this all on my own. It was easy enough to do that so …

It was important for Simon to stay connected:

> yeah I'd go and see my friends an' that, yeah … I go around all my family an' that talkin' to them … better than to shut myself out …

In terms of his communication skills now, Simon reported a mild aphasia: having difficulty explaining things at times, and also saying the wrong word. Simon's sister's main comment was that he confused pronouns, particularly *he* and *she*. Both felt that his speech problems were minimal, although Simon suggested he still had a little way to go.

Andrew

Andrew was a 47-year-old Yamatji man who had his stroke 17 years earlier at the age of 30. Originally from a regional area of Western Australia and from a very large family, he has lived in Perth for 6 years. As a result of his stroke, Andrew had a right-sided hemiparesis, aphasia, dyspraxia, and a homonymous hemianopia. After having the stroke in his home town, he was flown to Perth for 3 months, during which time he received therapy and was described as very motivated. However, he was discharged back to his home town with mild–moderate dysphasia and severe apraxia, and was referred on for speech-language pathology services. He presented with moderate-to-severe Broca's aphasia at the time of interview, but communicated relatively well via phrase-length speech. Several years after his return to Perth, Andrew was referred for physiotherapy and speech-language pathology at a time when he was admitted to hospital for other reasons. He was seen over a 4-month period for speech therapy, but attended only three of eight sessions offered. He was discharged due to poor attendance. Andrew also has rheumatic heart disease and asthma for which he is routinely monitored.

Andrew has two adult daughters, one has children, and both are living in his home town. He has been separated from his wife for many years. He currently lives alone in state housing. Prior to his stroke, he worked for state housing, then later worked as a gardener. He loved sports and played basketball, football, and cricket. Since his stroke, he has not worked, except for a short period when he worked as a gardener. He appeared very keen to return to his home town to live and to get a job there if he could, although he did not think this was likely.

Andrew was interviewed twice. At the first interview, Andrew presented as being quite independent and not wanting much social activity or assistance. He appeared to want to convey that he was doing fine, managing, and did not want a lot of contact with anyone. Despite three of his brothers being in Perth, he reported that they did not visit:

Interviewer:	Are they gonna come and see you or...? (referring to family)
Andrew:	No
Interviewer:	Your life is your own?
Andrew:	Straight out yeah

Asked by the interviewer whether he would be interested in going to any group activities, he said "I'm good" and that such activities were not for him. Andrew reported that he was independent in daily activities "don't need" (help); "battin by myself" (battling by myself).

He said he did see friends, however, when talking about this, he appeared to be indicating some reticence: "Keep away—distance—and 10 minutes—goodbye … No problems". When this was clarified, it appeared that his friends drank alcohol and got "rowdy", so Andrew tried to avoid these situations. He said that he had been "terrible" with alcohol in the past but had largely given it up in recent years.

At the second interview, Andrew was much more relaxed and discussed more about his social situation and everyday life. He talked about how much he enjoyed being with his grandchildren, especially visiting his home town. He reported attending a social group 1 day per week that was an activity group (involving games) at a centre which was for people with disabilities. He said he liked to "mingle" there and particularly with people of his age group there. He caught the bus to the group, but was dropped home. He visited friends or family regularly on one other day during the week. He also mentioned getting assistance with his reading and writing skills from a local librarian. Andrew denied that anyone had difficulty understanding him.

One theme mentioned at both Andrew's interviews was the importance of his family—looking after his daughters and grandchildren, and also his sadness at the recent loss of his parents: "I lost a Mum and Dad … I miss 'em, yeah …". When asked whether he ever felt depressed or sad, he replied: "Two daughters … lookin' after my two daughters and my son in law important … I ring up … yarn yarn … straight out". Finally, like Deryck and Simon, Andrew was keen to show himself as capable and active with comments like "I can do it" and "I can't stand uh … sittin' around …".

Discussion

These examples touch on the experiences of three Aboriginal men with aphasia, one fairly recently post-stroke and two with long-term stories of living with aphasia. While these are three different stories, there are some common themes between them. Firstly, the relatively young age at which all three men experienced their strokes is a significant issue with consequences for employment, young families, and social opportunities. Deryck and Andrew were both in their early 30s when they had their strokes and would have had considerable disruption to their lives. None of the three were living with partners—two lived with sisters and one lived alone. All were from rural areas initially. Another common feature is that they all had other significant and ongoing health concerns apart from their strokes, with conditions known to be of high incidence in Aboriginal populations such as diabetes and heart disease. All three had a history of alcohol abuse, a fact that was spontaneously mentioned by each participant, but they all had talked about their strokes impacting on their use of alcohol, their decisions to lessen their intake, and reduce their exposure to friendships centred around alcohol. All reported to be satisfied with their hospital experiences, but none of them had long-term speech-language pathology intervention, nor expressed any particular interest in having more. All three talked about strong family connections, and all were participating in their communities to some degree, Deryck particularly so. All conveyed a strong sense of independence, of wanting to be seen as capable and able to direct their own recovery.

An interesting feature of this study is that it explored the lives of people with aphasia who were well outside the speech-language pathology realm, examining what people do in the shorter and longer term without specific communication services to assist them. One of the original tenets of this project was that, while it may discover specific problems for Indigenous people with aphasia, it might also discover ways of living with aphasia that might inform research and practice both for the Indigenous and general population. The notion of *living successfully with aphasia* has been explored to date primarily from a western cultural perspective, with some inherent values about particular social networks, family, and personal autonomy. This study sheds a slightly different light on this issue, exploring attitudes in a more collectivist culture in which families and social networks can be extended, and where more value is placed on community decision-making than personal autonomy (see discussion in Fogarty & White, 1994).

It was of interest that while the participants knew the purpose of the interviews, they rarely initiated any discussion of their aphasia. When asked, responses were minimal. This contrasts with studies by Cruice, Hill, Worrall, and Hickson (2010) and Brown et al. (2010), who reported on interviewing non-Indigenous people with aphasia about their quality-of-life or what it meant to live successfully with aphasia. These participants, from a range of ages and times post-onset (although the mean age was higher and the mean time post-onset was lower than in the current study), explicitly spoke a lot about their communication problems and the implications of these for their everyday lives. The lack of discussion about aphasia itself in our study could have occurred for a number of reasons. As each of these men had significant other health issues, it could have been that their aphasia was not of primary concern in terms of difficulties. The issue of communication being secondary to physical impairments and conditions has been acknowledged most recently by Walshe and Miller (2011) in relation to dysarthria, and certainly the physical issues following stroke feature highly for people with aphasia (Worrall, Sherratt, Rogers, Howe, Hersh, & Ferguson, 2011). Secondly, disabilities are known to be constructed differently in traditional Aboriginal culture (Ariotti, 1999; Boddington & Räisänen, 2009) from the way they are perceived in western culture. While physical conditions are identified individually (e.g., a lame person, a blind person), cognitive and communication-related conditions may be identified as "slowness" reflecting "a mental condition" or alternatively not identified as discretely, hence more difficult to discuss. Indeed the questions related to barriers and facilitators in terms of communication (difficulties/things that helped) did not appear to be central to the two participants with more severe difficulties. A possible reason, however, relates to the time post-onset for the two most severely affected speakers. Many years on, their aphasia was perhaps an integrated part of their identity, rather than something that required separate discussion.

However, communication and being in touch with others featured in all three stories, especially in the longer-term with the two men with significant aphasia many years post-stroke. They accessed services/support groups/activity groups in order to meet other people, "yarn" and "mingle", as well as pursued usual and pre-morbid social and personally meaningful activities such as visiting family and friends, and attending music nights "at the pub". While the need to avoid alcohol appeared to have curtailed some of their social relationships, their stories were consistent with the importance of social participation and resuming activities after stroke identified in previous studies of quality-of-life in the general population (e.g., Brown et al., 2010; Cruice et al., 2010; Cruice, Worrall, & Hickson, 2006). Hence, there appeared to be an implicit valuing of communication, but no accompanying story of obvious barriers identified as relating to the aphasia.

The importance of family was obvious for all three participants, although in different ways. For the two participants who lived with their sisters, it was clear that they were assisted with daily activities, medication, meals, the cost of accommodation, and companionship. While the third participant did not live with family, he discussed family throughout his interview, wanted to return to his home town, and mentioned missing his parents who had recently passed away. Two of the three noted the importance for them of looking after their children—of being around to help them. It appeared important for them to state that they maintained this role in the family, despite their strokes and related health issues.

Issues of identity were significant across all three, with Simon and Andrew emphasizing their roles within the family, and Deryck repeatedly identifying himself as a painter and a singer. In particular, the two people with long-term significant aphasia conveyed this renegotiation of self and identity very clearly (Shadden & Hagstrom, 2007).

The fact that we were reporting here on three men might suggest that the attitudes expressed, for example, of getting on with life, not wanting therapy assistance, not wanting to elaborate on disability, might be gender-influenced. This may well be the case, and access to a wider range of stories may shed more light on this. Our reference group did warn us at the outset that we would be less likely to recruit Aboriginal men as they would not typically want to discuss their problems. We found these men, however, were quite happy to speak with us and demonstrated no obvious reticence in regard to the issues discussed.

Another feature of interest was the overall satisfaction with hospital care that each participant expressed. There were no negative issues raised about the hospital stay *per se*, and in fact many positive statements. However, it is significant that two of the three men reported in this study self-discharged against medical advice, and discharge details were unclear for the third man. Recent studies reporting on the experiences of Aboriginal patients with cancer (Shahid, Finn, & Thompson, 2009a; Thompson, Shahid, Greville, & Bessareb, 2011) in fact found numerous difficulties faced by Aboriginal people in acute hospitals in Western Australia related to communication, facilities, and a number of other factors. Previous studies have also documented major difficulties encountered in the acute setting involving stroke as well as numerous other conditions (Faux et al., 2009; Tanner, Agius, & Darbyshire, 2004–2005; Watson, Hodson, & Johnson, 2002). However, Shahid et al. (2009a) also acknowledged many positive aspects of hospitalization experiences and were optimistic about changes being made in terms of cultural safety and security issues in hospital. While there is the possibility that participants in this study were reluctant to criticize their hospital care, there is no particular reason to question this finding in this case.

Methodological issues

It is important to note that numerous methodological issues arose throughout the project that should be addressed in the planning of future studies. These related to community consultation, recruitment, and the interviews themselves. The construction of an Indigenous reference group, the importance of the Indigenous interviewer, interview training and education about aphasia, payment of honoraria for participants, recruitment strategies, the structure of the interviews, number of interviews required, and interpretation of findings are all significant issues. We intend to elaborate on these in another paper, but would refer interested people to an excellent article by Shahid, Bessarab, Howat, and Thompson (2009b) referring to similar matters in a study undertaken in WA in relation to cancer care.

The inclusion of two family members in the interviews with two of the participants, Deryck and Simon, may have precluded the person with aphasia from speaking freely—potentially for family reasons, and also because research has documented how families of people with aphasia often "speak for" the person, inhibiting the person with aphasia's participation in the conversation (Croteau & LeDorze, 2006). However, Deryck was interviewed alone on two other occasions and his level of participation in the interview remained similar, and Simon did not appear to be inhibited at all with his sister present, although it is difficult to determine whether anything different may have emerged if he had been alone. Nevertheless, it was important to give participants the option, and important to note that all participants in the larger study who involved family members opted for the family member to be present.

Conclusion

Obviously, from only three stories, we are not aiming to generalize our conclusions. However, these stories are an important first step in exploring the experiences of Aboriginal people with aphasia. They raise issues about how people with aphasia manage in the longer term when they do not access speech-language pathology services after they leave hospital. In two cases, this involved a very long time post-onset of the aphasia. Certainly, not all the issues raised in this paper are specific to Aboriginal people. However, when seen in relation to each other (as a confluence of issues, for example, comorbidities, age, social situation, cultural background), it is possible that these stories are representative of some Aboriginal people's experience of aphasia. One significant finding is that, while Aboriginal people with aphasia may not be regular attendees at traditional speech-language pathology services, they do attend "services", activities, and groups that have a social or recreational purpose and provide them with a supportive community. Communication remains important and aphasia recovery is facilitated through these different channels. Rather than focusing on speech-language pathology services as separate from other community initiatives, it may be more productive to consider creative ways of embedding elements of communication rehabilitation, at least education and information, more effectively in existing services. These stories also highlight positive adjustments made by these three men. Perhaps speech-language pathology, with its focus on revealing deficit and working on areas of weakness, is an uncomfortable challenge for some people. This paper raises other questions of relevance to aphasia services pertaining to flexibility, relevance for very young people with stroke, family and community involvement, and follow-up. In addition, the specific concerns of aphasia therapy, with its risks of inherent separation of language ability from other aspects of health and life, do not necessarily fit with the holistic views of health for Indigenous populations. Indeed, those working within a social approach would argue that such separation is not helpful in non-Indigenous populations either. Nevertheless, exploring real experiences and stories raises awareness of the needs of Indigenous people with aphasia and may help in achieving the partnerships, understandings, and connections required to improve the situation for these people.

Acknowledgements

This research was supported by an AIATSIS grant, G2010. 7595. We wish to thank the three participants for sharing their stories and their homes with us in order to help others who have experienced strokes already or may in the future.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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