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Development of the Aboriginal Communication Assessment after Brain Injury (ACAABI) - a screening tool for identifying acquired communication disorders in Aboriginal Australians

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Abstract

Purpose: Acquired communication disorders (ACD), following stroke and traumatic brain injury, may not be correctly identified in Aboriginal Australians due to a lack of linguistically and culturally appropriate assessment tools. Within this paper we explore key issues that were considered in the development of the Aboriginal Communication Assessment After Brain Injury (ACAABI) – a screening tool designed to assess the presence of ACD in Aboriginal populations.

Method: A literature review and consultation with key stakeholders were undertaken to explore directions needed to develop a new tool, based on existing tools and recommendations for future developments.

Result: The literature searches revealed no existing screening tool for ACD in these populations, but identified tools in the areas of cognition and social-emotional well-being. Articles retrieved described details of the content and style of these tools, with recommendations for the development and administration of a new tool. The findings from the interview and focus group views were consistent with the approach recommended in the literature. .

Conclusion: There is a need for a screening tool for ACD to be developed but any tool must be informed by knowledge of Aboriginal language, culture and community input in order to be acceptable and valid.

Key words: Acquired communication disorder, Aboriginal Australians, screening tool

Introduction

Stroke and traumatic brain injury (TBI) occur up to three times more frequently in Aboriginal and Torres Strait Islander (hereafter referred to as Aboriginal) Australians when compared to the non-Aboriginal Australian population (Katzenellenbogen et al., 2010; You et al., 2015), although figures are thought to underestimate the true incidence (Thrift, Cadilhac, & Eades, 2011; Katzenellenbogen et al., 2016). Lack of screening/assessment tools, poor access to interpreters who speak Aboriginal languages, limited knowledge of Aboriginal English speech patterns by health professionals, limited expertise and awareness of workforce in identifying acquired communication disorder (ACD) and lack of follow-up of Aboriginal brain injury survivors post-discharge from hospital all make identification challenging, and suggest that under-identification is a significant issue.

Reliable epidemiological data relies on identification of conditions to determine incidence which then informs the planning and delivery of services. Consequently, the lack of reliable epidemiological data on the number of Aboriginal Australians presenting with an ACD has contributed to the difficulty of developing accessible and appropriate evidenced-based services. The World Report on Disability highlights the need to improve data collection as a starting point to facilitate a better understanding of the needs of under-served groups such as indigenous people with ACD, and to develop accessible and equitable services (Wylie, McAllister, Davidson, & Marshall, 2013). Services should be designed to accommodate different cultural groups and their views, and to cater for the needs of individuals with ACD and their families, and carers. Current knowledge suggests that representation of Aboriginal brain injury survivors in rehabilitation services is low with many Aboriginal people not accessing services following discharge from hospital (Armstrong, Hersh, Hayward, Fraser & Brown 2012;

Armstrong, Hersh, Hayward & Fraser, 2015). The use of screening tools which capture important diagnostic information is one method of obtaining more accurate epidemiological data on the incidence and prevalence of ACD post stroke or TBI. However, to date, no culturally and linguistically appropriate tools help to identify Aboriginal Australians living with an ACD, and a similar situation exists internationally in relation to indigenous peoples.

ACD focussed screening tools exist to support the accurate identification of communication impairment. They offer a snapshot of the presence or absence of specific impairments. In the area of ACD, aphasia has been the main area of focus to date. Administration of a screening tool should enable a health professional to identify any deficits and determine who should be referred to speech pathology services for more in-depth evaluation and management (Salter, Jutai, Foley, Hellings, & Teasell, 2006). Within the Australian Aboriginal population, the lack of culturally and linguistically sensitive communication screening tools may exacerbate the underestimation of the number of Aboriginal people with ACD. As a result of this, fewer people are referred to appropriate services.

The key to developing effective service delivery models for Aboriginal clients is the need to ensure that each individual feels culturally secure with services provided (Coffin, 2007). In terms of devising new and appropriate speech pathology assessments, it is recognised that cultural and linguistic factors need to be considered carefully as these contribute to feelings of cultural security (Ivanova & Hallowell, 2013). Translation of assessment tools from the dominant culture is not always appropriate or sufficient (Ivanova & Hallowell, 2013), although successful modification of screening tools for use with Aboriginal and Torres Strait Islander Australians developed previously for other health conditions are relevant (for primary review see Dingwall &

Cairney, 2010). The need for different styles of assessment, different stimuli, and different rules for administration has been widely acknowledged (e.g. Dingwall, Lindeman, & Cairney, 2014; Dingwall & Cairney, 2009, 2010; Drew, 2000; Kotz, Muns, Marriott, & Marley, 2016), with aspects varying across cultures. Aboriginal Australians live across Australia in metropolitan, regional, remote, and very remote areas (ABS, 2011), and speak around 145 different Aboriginal languages according to the National Indigenous Language Survey (Department of Communications, Information, Technology and the Arts, 2005), although some of these are used only by a small number of people in very remote communities. Hence, consultation with relevant community stakeholders is essential, in order to ensure appropriate cultural representation and input into the design of a new tool. A good example of this is the process undertaken in the development of the Kimberley Indigenous Cognitive Assessment (KICA) that is now used across Australia, modified to, and validated in, local contexts (LoGuidice et al., 2006).

This paper outlines the processes undertaken as part of the development of the Aboriginal Communication Assessment After Brain Injury (ACAABI) – a screening tool designed to assess the presence or otherwise of a communication disorder after brain injury in Australian Aboriginal populations. The ACAABI was developed as part of a larger project examining the extent of ACD in Aboriginal populations following brain injury, the experiences of Aboriginal brain injury survivors, and service delivery models (Armstrong et al., 2015). The development of the tool involved a review of literature for principles relevant to development of screening tools for Aboriginal populations and specifically for ACD, and an extensive consultation process with Aboriginal communities throughout the state of Western Australia (WA). The community engagement was undertaken within an Aboriginal research framework,

utilising principles of two-way learning and cultural security (Coffin, 2007). While results of piloting the tool will be reported elsewhere (Armstrong et al., in preparation), the development process was essential to the product and warrants detailed reporting, particularly given its relevance for tool development in other populations. The unique historical, geographical, cultural, linguistic and health contexts of Indigenous peoples throughout the world warrant careful consideration before simply using existing tools with these populations. Hence, it is hoped that discussion of the tool's development process will contribute to future endeavours including contributing to a framework that could be used for validation of the cultural appropriateness of future tools.

Processes involved in the development of the ACAABI

The development of the ACAABI was informed by two key components described here: (1) a broad review of relevant literature; (2) focus groups involving key stakeholders. The review of the literature aimed to identify available tools used in the assessment of communication disorders in Aboriginal populations, and to identify general principles to be considered in developing a culturally appropriate screening tool. The focus groups were undertaken to assess the relevance of the literature and ensure the involvement of the stakeholder group in the design of the tool. The complete process for the development of the tool is outlined in Figure 1, with the focus of the current paper highlighted.

INSERT FIGURE 1 HERE

(1) Literature Review

Method

A broad literature review was undertaken in order to determine whether any relevant tools currently existed, and to learn from previous research regarding experiences and

methods involved in the development and validation of tools for use with Aboriginal participants. The search aimed to i) identify any existing screening/diagnostic tools in the area of communication disorders tailored for use with Aboriginal Australians, ii) identify any existing screening/diagnostic tools tailored for use with Aboriginal Australians in other health conditions, iii) identify any existing screening/diagnostic tools for communication disorders or other health conditions tailored for use with indigenous peoples internationally, and iv) explore characteristics of screening tools/assessments of impact used routinely in the area of ACD. The inclusion of tools involving other health conditions was intended to gather information on general principles involved in adapting existing tools in culturally appropriate ways and/or creating new tools. Articles that included details regarding the construction of tools were of particular interest, especially those involving community consultation. We were interested in impairment-based as well as activity-based functional tools, and tools that explored the effects of the ACD/health condition on the person involved, including quality of life. As we were aware that the existence of such tools was limited, we wanted to draw on as much culturally appropriate experience as possible to inform the development of the ACAABI.

The following electronic databases were searched: PubMed, CINAHL-Plus, ERIC, PsycINFO and EMBASE. Additionally, for the two searches on Aboriginal Australians, the Australian data repositories InfoRMIT and HealthInfoNet were searched. Keywords used in the search are outlined in Appendix 1. Searches were not restricted to English language (although the great majority of articles retrieved are English language). Searches were not date-range restricted.

Result

Screening/diagnostic tools for communication disorders in Aboriginal or Torres Strait Islander adults.

The search confirmed that there were no existing communication screening tools designed for Aboriginal adults with acquired brain injury or a related disorder, and only one for Aboriginal children (Salter, 2013). Together with linguists, speech pathologists and local community members, Salter designed a set of subtests to assess language skills in Aboriginal children in the Fitzroy Valley of the Kimberley Region in northern Australia, as well as two questionnaires – one for teachers, and one for caregivers. The subtests (surrounding story-telling and a non-word repetition task) were administered in Fitzroy Valley Kriol by a local speaker, with the speech pathologist observing and scoring. Existing tests such as the Brigance Developmental Screening Tool (D’Aprano, Hayes, & Buckby, 2011) and more recently the Ages and Stages Questionnaire (Squires, 2009) which contain a language component have also been used with Aboriginal children. D’Aprano, Silvern, Johnston, Robinson, Oberklaid, & Squires (2016) reported on modification of the Ages and Stages Questionnaire for use in the Australian Aboriginal context. Articles discussing issues concerning language ‘disorder’ versus language ‘difference’ in Aboriginal children were also found (e.g. Gould, 2008). One article from New Zealand detailed a questionnaire designed to assess the importance of a variety of functional communication activities for brain injury survivors and included Maori stakeholders (Larkins, Worrall, & Hickson, 2004). While it was not specifically related to the development of a screening tool per se, it did provide some information on relevant methodology in this area.

Screening/diagnostic tools tailored for other health conditions.

While not directly related to communication, 27 articles were deemed to be relevant to our study in that they discussed methodologies involved in either modifying existing or

constructing new tests/questionnaires for Aboriginal Australians (adults and children). Areas covered included vision screening, and medical and developmental checklists to investigate incidence of conditions such as Fetal Alcohol Syndrome Disorder (FASD) (Fitzpatrick et al., 2013), other developmental disability in children (D'Aprano, Carpetis, & Andrews, 2011), and musculo-skeletal conditions (Vindigni et al., 2006). These articles highlighted the difficulties involved in using already established tools cross-culturally and in this case, in Aboriginal contexts. They highlighted issues of administration, wording, and nature of the testing. For example, D'Aprano et al. (2011) used the Brigance developmental screening tool with Aboriginal and Torres Strait Islander children from the Northern Territory and found that all 124 children tested were potentially identified as having a developmental disability. One potential reason highlighted for this finding was the nature of the testing e.g. "Indigenous children may not be accustomed to responding to questions that seem irrelevant or providing answers that are known to the examiner, which is required of them in this method of screening" (p.15). Fitzpatrick et al. (2013) discussed the importance of wording issues again in the development of a questionnaire for families to detect FASD in children. They highlighted the need to use wording and grammar familiar to Aboriginal English speakers e.g. 'who grew them up?' for the question 'who raised the child?', local terms for 'alcohol', for example, as well as sensitivity to asking certain questions e.g. not asking questions about 'women's business' (e.g. history of miscarriage, pregnancy complications) in the presence of males. They emphasised the importance of making the interview as non-threatening as possible, ordering the questions so as to make them flow logically and having a 'community navigator' present in order to explain questions further or interpret as required. Explaining and ensuring confidentiality processes was also crucial.

Sixteen of the 27 articles retrieved were related to cognition and mental health issues. A review of tools trialled to assess cognition and mental health in Aboriginal and Torres Strait Islander populations by Dingwall and Cairney (2010) outlined seven tools assessing mental health and social-emotional well-being, and five cognitive assessments. Details of validity and reliability are provided in that review, as opposed to our focus which is on tool development, content and format. Of the tools outlined by Dingwall and Cairney, eight were particularly relevant to our undertaking, involving the screening of adults as opposed to children or adolescents. Only four tools were specifically designed for Aboriginal and Torres Strait Islander populations, and five others had been used or adapted for use with Aboriginal and Torres Strait Islander Australians. We found an additional three tools beyond this review, to screen for: depression and anxiety associated with substance abuse (Dingwall & Cairney, 2011), mental health risk associated with drug and alcohol use (Schlesinger et al., 2007), and social and emotional wellbeing (Janca, Lyons, Balaratnasingam, Parfitt, Davison, & Laugharne, 2015).

Tool development. Methodologies for development of the tools specifically designed for use with Aboriginal Australians generally involved extensive consultation with health workers, potential health target groups, Aboriginal reference groups, community Elders, linguists, and academics working in the field of Indigenous health. With original tool development, the processes were iterative in nature i.e. items were selected following literature review, initial drafts of items/complete tools were discussed with a variety of stakeholders, amended, discussed further, then finally approved and trialled. Where tools were adapted, stakeholders were typically consulted and assisted with changing wording, response type etc.

Test format and administration. The number of items in the tools examined ranged from 10-25. Length of time for administration was noted in some tests, with the KICA Screen, for example, reported as taking 10 minutes, whereas the KICA Cog takes 25-30 minutes. The Social-Emotional Well-Being tools predominantly used Likert scales based on self or carer report such as the Strong Souls assessment tool (Menzie's School of Health Research, 2013) which utilised self-report. For the mental health items in this tool, participants are asked how *often* they have felt or experienced symptoms in the past few months, potential responses being: *not much, little bit, fair bit and lots*. The Negative Life Events Scale (NLES) on the other hand, simply requires a yes/no response to items subsumed under an over-arching question: *Have any of these things ever been a worry to you or anyone else living in this house over the last two weeks?* Samples of the items responded to include: *serious illness, serious accident, death of family member or close friend, gambling problem, discrimination/racism*. In discussing the NLES, Kowal, Gunthorpe, & Bailie (2007) discussed the need to adjust the wording of some items from the original used by the Australian Bureau of Statistics for general Australian data collection. For example, the original question was "have any of these things been a problem to you...". The word 'problem' was changed to 'worry' in line with local Aboriginal English in the Northern Territory where the tool was being trialled for research purposes. Another change involved the phrase 'witness to violence' which was altered in order to 'seeing fights or seeing people beaten up.' Due to the diversity of Aboriginal and Torres Strait Islander language groups and varied locations, the need to adapt to local variations was highlighted, with Campbell, Hayes, and Buckby (2008) making the important point that 'one size does not fit all' in this context. Nevertheless, some tools have been noted to be useful across groups/regions e.g. the KICA Screen.

Selection of culturally appropriate cognitive/direct skill based items. The KICA sub-section on cognition appears to be the only tool to date which has used a consultative process to design specific cognitive tasks within a test. Tasks involving testing of such aspects as word fluency, language, short and long term memory were all adapted from traditional standardised tests to form culturally relevant items. For example, when discussing Sheldon's (2001) recommendation that clients could be asked to recall all the skin names in their language group as a memory task, Smith et al. (2007) noted "This is not reasonable in the Kimberley as different numbers of skin groups exist between Kimberley language groups" (p.117). Naming children in the family was also not appropriate as a client may have had children who were deceased and hence could not be named. Instead, the relatively neutral category animal-naming task in the word fluency section was deemed an appropriate indicator of semantic long term memory. The picture items used for naming were well known within the local community i.e. *boomerang, boy, emu, billy/fire, crocodile and bicycle.*

Screening/diagnostic tools for communication disorders or other health conditions tailored for use with indigenous people internationally.

There is a growing but still relatively limited body of literature internationally surrounding the development of culturally appropriate screening tools and assessment procedures as cultural awareness increases and practitioners and researchers increasingly acknowledge that tests/interviews based on western concepts of physical and mental health are not appropriate to be used universally (Abbott, 2011). Mitchell and Beals (2011), for example, used the Kessler Screening Scale for Psychological Distress with American Indian communities in Arizona, receiving local community approval for cultural appropriateness of each of the items through focus group consultation. It was found to be an accurate measure of severity and predicted health

related quality of life as determined by the Medical Outcome Study's Short Form-36 (see Ware, 2000). On the other hand, the Short Michigan Alcohol Screening Test (SMAST) tested in two distinct American Indian tribal groups (wording modified) (Robin et al., 2004) was not found to be a valid to screen in these groups. Sensitivity was high but specificity was not, reflecting an over-estimation of alcoholism in both tribes. Work is continuing in this area, particularly again in the mental health fields, but with no apparent attention being given to language/communication specifically.

Screening tools for acquired communication disorders in general.

The existing screening tools for ACD designed for the general population and currently in use were primarily impairment focused. However, we also included tools that assessed functional communication activity and communication-related quality of life, including communication-related depression (see Appendix 2). The majority of questionnaires and checklists considered were not strictly screening tools but provided a questionnaire format that could be incorporated into the ACAABI in order to assess impact as well as presence of communication disorders. The impairment-based tools contained subtests requiring correct/incorrect responses, while the remainder of the tools, consisting largely of questionnaires and checklists, had rating scales. When considered together these tools provided both a range of formats and a range of areas of assessment to present to target focus groups as examples of existing tools. This was necessary in order to clarify the screening task at hand, particularly for non-speech pathologists unfamiliar with the aim of screening or existing methods to assess communication. The communication disorder tools we used in this exercise were related predominantly to aphasia, although two related to dysarthria, and one was specifically designed for people with cognitive communication impairment following TBI (Drummond & Boss, 2004).

Administration times for these tools were stated to range between 30 seconds (verbal fluency test) and 30 minutes, with most between 5-15 minutes. Some tools were designed for use by speech pathologists and some for other health professionals (e.g. the Frenchay Aphasia Screening Test – FAST - Enderby, Wood, Wade, & Hewer, 1987; the Ullevaal Aphasia Screening test - Thommessen, Thoresen, Bautz-Holter, & Laake, 1999). The aphasia tools were either focused on impairment (e.g. the FAST), communicative function on everyday tasks (e.g. Communicative Effectiveness Index – the CETI – Lomas et al., 1989), or quality of life/impact related to communication including both self and carer perspectives (e.g. Communication Outcome After Stroke – Long, Hesketh, Paszek, Booth, & Bowen, 2008 and Carer COAST - Long, Hesketh, & Bowen, 2009). The actual screening tools that were impairment-based typically contained tests for each of the four modalities (speaking, auditory comprehension, reading and writing) with subtests consisting of between 10-45 items (language component of Addenbrooke's Cognitive Examination-Revised - ACE-R - Gaber, Parsons, & Gautam, 2011; Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006), with numerical total scores. Some subtests related to specific tasks such as naming, repetition etc. (e.g. ACE-R), and one test specifically aimed to screen underlying linguistic deficits at the semantic, phonological and syntactic levels, hence subtests were grouped accordingly (the ScreeLing Test – Doesborgh et al., 2003). The functional tests had between eight (Communicative Effectiveness Survey - Donovan, Kendall, Rosenbek, & Young, 2008 - CES) and 16 (CETI) items, some with carer/family questions/ratings to complete and generally used rating scales. One was a rating of speech during conversation (Functional Communication Scale – Drummond & Boss, 2004) incorporating 13 aspects to be scored. The QoL/impact questionnaires had between three items (Burden of Stroke Scale – Doyle, 2002 - Communication-Associated

Psychological Distress Scale) and 53 items of the original SAQOL (Stroke and Aphasia Quality of Life Scale – Hilari & Byng, 2001), shortened to 39 in the SAQOL 39 (Hilari, Byng, Lamping, & Smith, 2003).

The important features of sensitivity and specificity of a screening tool were highlighted in all studies (Cairney et al., 2007) i.e. the tool should not only identify individuals with the disorder under focus (high sensitivity), but also ensure that false positive identification does not occur.

(2) Interviews and Focus Groups

Following the literature review, interviews and focus groups were conducted with health professionals with experience in working with Aboriginal Australians who had experienced stroke or traumatic brain injury as well as people with ACD. These were undertaken to gain input into what might inform the development of a practical and culturally sensitive and appropriate screening tool, and complement the information gained through the literature review.

Method

Purposive sampling was used to recruit participants in a metropolitan and rural site. Within these locations, participants were recruited from local hospitals, Aboriginal Community Controlled Health Services and not for profit, community based service providers. Participants were Aboriginal and non-Aboriginal health providers comprised of 13 Aboriginal Health Practitioners, and five non-Aboriginal Speech Pathologists, as well as two Aboriginal people with ACD. Later iterative consultation occurred involving a wider group including linguists, nurses, GPs, Aboriginal research assistants and academics. However this paper focuses on the initial formal focus groups and interviews.

Four focus groups and four individual interviews were conducted by members of the research team, in combination with an Aboriginal Research Assistant where possible. An interview guide was developed and used within the interviews so that all participants were asked the same stem questions concerning their experiences with screening to date, and their recommendations regarding form and content of a future tool (see Appendix 3).

For the Aboriginal health practitioners, the focus groups took place as part of a two hour workshop in order to provide background to the project and a focus for discussion surrounding ACD. The first part of the workshop provided information to participants about communication disorders and the second part consisted of discussion of the screening tool, gaining input from the health practitioners. Examples of existing screening tools were presented to interviewees in order to demonstrate the kind of tool that was being considered.

Interviews were transcribed verbatim and analysed by members of the research team using a qualitative, descriptive analysis (Sandelowski, 2000). This involved multiple readings of all data and initially coding line by line. Similar codes were merged into categories and then into broader themes. All transcripts were analysed independently by the first and second authors and then discussed together in order to reach a consensus.

Result

Resulting themes related to i) the format and content of a potential screening tool, ii) the administration of a tool, and iii) factors that may impact on the administration of the tool and the interpretation of findings. Key principles extracted from these themes are depicted in Figure 2.

Format and content

Most participants (Aboriginal Health Practitioners in particular) agreed on the need to incorporate the family perspective within the screening tool. They felt the family would have an important perspective and may provide information the individual with an ACD may not provide themselves. However, some Aboriginal participants also advised that it may be best to leave questionnaires with informants rather than seek an immediate response, as some people may be reluctant to give information to someone they didn't know. It was also strongly felt that the tool should be 'yarning' based, that is, administered in a conversational/ informal style, with questions asked and content provided in a non-confronting manner. It was also identified that, in some situations, the over-reliance on questions in a screening tool may result in inaccurate information being obtained. In answering a question, a person with ACD or their family members may say what they think is expected or may not reveal weaknesses due to feelings of self-consciousness and embarrassment/ humiliation (shame). Aboriginal participants emphasised that Aboriginal people were often self-conscious about their communication in unfamiliar situations with non-Aboriginal or unfamiliar people, such as hospital/unfamiliar health worker interactions, and often felt judged on their communication. One participant said:

“We're very conscious of what comes out of our mouths a lot of the time. Sometimes you know we're very conscious of how we're being judged cos that's...we've been judged for so long it's very much a part of who we are....so if someone's got a stroke there's a double fear.”

In terms of asking people to complete written forms, caution was given:

“Yeah well how do you know that that person filling the form out has...they can't write. You're asking them to fill the form out – they can't write so therefore you've shamed them.”

While a conversational or yarning framework was considered superior to written responses and indeed essential, speech pathologists in particular felt that some

structured tasks e.g. naming and picture descriptions, may be useful for more severely impaired individuals who may not have a lot of speech, but might be able to respond to a single task. Some Aboriginal Health Practitioners also agreed that such tasks could be helpful for them in directing the assessment and having specific things to listen for on specific tasks. However, some also felt that pictures should be used with caution as activities might be perceived as childish and hence insulting. If pictures were to be used, they should involve familiar vocabulary and items should not be patronising. Composite pictures used to elicit descriptions/speech should involve Aboriginal people in familiar situations, such as a photo of the local shop or a hospital rather than those involved in common currently used tests involving western-focused contexts such as the Cookie Theft picture from the Boston Diagnostic Aphasia Examination (a commonly used aphasia tool – Goodglass, Kaplan, & Barresi, 2000) or the picnic picture from the Western Aphasia Battery (Kertesz, 2006). Single pictures should not stereotype Aboriginal people, for instance through words like ‘kangaroo,’ ‘boomerang’ etc.

The Aboriginal Health Practitioners also suggested the tool should be quick, without too many items. It was felt that it was important for the time constraints in the work situation to be understood, with some practitioners suggesting that a screening tool should fit into currently existing ‘toolkits’ of assessments.

Administration

Participants affirmed that the tool would ideally be administered by an Aboriginal person, with issues related to cultural safety and security (Coffin, 2007) taken into account. For example, participants commented on the importance of taking time to build trust between the person administering the test and the person with ACD and their family. Some suggested that for the tool to elicit useful information, it should be used

over at least two occasions. Sharing of information between the client and the Aboriginal Health Practitioner was recommended through discussing where each was from, community connections and so on. Family should also be present if they or the brain injury survivor wanted this to happen. As the person with ACD may not be familiar with the testing situation or see the relevance of the tasks, the importance of explaining why the tool was being administered and benefits from completing the assessment before asking permission to complete the screening tool was highlighted.

The need for the tool as a whole as well as the individual tasks to be non-confronting was also emphasised, interwoven with the explanation of the task, contextualising the task so as not to be part of a right/wrong/judgemental paradigm. Varying literacy levels amongst Aboriginal people was another important issue. Many existing communication screening tools include sections for reading and writing. Aboriginal Health Practitioners emphasised that such testing is not relevant for some people and that such testing may not be appropriate by contributing to an undesirable and confrontational situation.

A need for the tool to be translatable was raised. With the diversity of language groups across WA and indeed Australia as a whole, the screening tool had to be sufficiently general so as to be translatable and appropriate across numerous Aboriginal languages. A major issue in the diagnosis of communication disorder across cultures is the identification of disorder in a language that is often foreign to the test administrator. Interpreters are typically used in such situations and some efforts have been made to ensure that tests are translatable (Benton et al., 1994; Edwards & Bastiaanse, 2007). While there are inherent difficulties in this, any communication tool designed for use with Aboriginal populations must address this issue.

Education was also highlighted as an important part of the assessment process. It was felt that the brain injury survivor and/or family may want to ask questions about issues such as brain injury, consequences and therapy available. While the person administering the test may not be able to answer all questions, every effort should be made to provide useful information to participants on their condition and services they could access in the future. A resources booklet with such information could also assist practitioners.

INSERT FIGURE 2 HERE

Other Cultural factors

The participants raised other factors that need to be considered in the general approach to the assessment process, both in administration of the screening tool and in interpretation of results. These include the way in which factors such as the age, gender, relationship between the client and the person administering the screening tool and status of the person with ACD may influence responses to different tasks. For example, a male Elder might find it difficult being asked questions by a young female. Cultural rules may make it difficult for a person from one cultural group/clan to test someone from another group. Inter-family relationships between the brain injury survivor and the test administrator might limit topics that could be discussed. It was also highlighted that identifying impairments in ‘pragmatic’ elements of communication, such as those related to amount of verbal output, directness, succinctness, politeness, and social appropriateness which have been noted in cognitive communication disorders in adults from western cultures (e.g. Elbourne, Togher, Kenny, & Power, 2016), may be difficult due to lack of information on cultural norms for Aboriginal Australian populations. Careful consideration must be taken when identifying ‘pathology’ in a cross-cultural

context, as has been noted in the paediatric area in the case of diagnosis of language disorder (Gould, 2008).

Ethical and logistical considerations

A core point expressed was the implication of the identification of any disorder. Clearly, if a disorder is identified, subsequent assistance for the person with the communication disorder and their family needs to be available. This was of particular concern for Aboriginal populations from rural and remote areas where rehabilitation services are limited. The usefulness of an identification tool in the absence of follow up services was queried, an issue that received a deal of discussion. In the context of the research, identification was also discussed as a way of highlighting numbers requiring services and driving planning of future services. This was stressed as a significant issue throughout the project. In addition, the need for information regarding brain injury was seen as an essential part of the screening process, in order for those screened and their families to benefit from the process.

Conclusion

Given the high incidence of brain injury in Aboriginal Australians and their reported under-representation in rehabilitation services after discharge from hospital, identification of significant sequelae such as communication disorders is crucial to the promotion and provision of services that can assist in long-term management issues. Developing an accessible communication screening tool for use by a range of health professionals working with Aboriginal and Torres Strait Islander Australians is an important step towards gaining an awareness of the size and scale of the problem in order to develop services which address the needs of this population in the future.

As the literature review had not identified any existing tool designed for use with this population that incorporated both relevant content and a culturally sensitive

administration framework, it was apparent that such a tool is needed, and that it may assist in engaging Aboriginal Australians with the rehabilitation process. The processes described in this paper outline the kinds of issues raised by both the current broader research literature involving screening of a variety of disorders (nationally and internationally) and by relevant Western Australian stakeholders, particularly Aboriginal Health Practitioners experienced in working with Aboriginal people with chronic disease and more specifically with brain injury survivors. Both the literature and the information provided by focus groups highlight the sensitive nature of ‘testing’ of communication skills within Aboriginal populations, given historical experiences, as well as cultural norms concerned with gender, community status, family relationships, and language differences. In the construction of any diagnostic or screening tool, multiple issues must be taken into account in order to design a tool that potentially has general relevance in Aboriginal communities while taking into account local differences, given the diversity of Aboriginal Australia. Challenges are multiple and the design of any such tool will need to be an iterative process.

While the consequences of identification of ACD will inform development of future services, identification in the current context in which rehabilitation services are largely based in metropolitan areas continues to be problematic for brain injury survivors. Participants interviewed in this study emphasised the need for information regarding brain injury and recovery processes to be provided to communities as part of the screening process, as well as the importance of sensitivity to be paid to informants who may not have access to services given current limitations, particularly those in rural and remote areas. Identification of issues does not guarantee services, hence any systematic assessment of screening processes must have a purpose in informing future planning of services, but also play a role in increasing awareness of the effects of brain

injury within communities, and in educating participants about principles of rehabilitation and ways of managing the related issues at a local level.

The development of assessment tools is a complex undertaking, and piloting is essential. While extensive consultation occurred in this study, it is possible that further issues may come to light in the piloting of the tool, which may have not arisen during the consultation process. A difficulty arose initially when it became obvious that many Aboriginal Health Workers were unfamiliar with the notion of acquired communication disorder. Hence, to engage in relevant discussion, clear, detailed and often ongoing explanations had to be provided by the interviewers regarding the disorders involved and the purpose of the tool development. Subsequent active discussions ensued. Going forward, the tool has been developed incorporating the principles outlined in this paper. It is currently being piloted, with issues related to feasibility, validity and reliability being investigated. An outline of the tool, its validity and suitability will be the subject of future publications.

Appendix 1. Key words used in the literature searches included

speech disorder “speech disability” “speech dysfunction” “speech apraxia” “communication disorder” “communication disability” “language disorder” “language disabilities” “language dysfunction” “aphasia* dysphasia* dysarthria* “language development disorder” “language development disorders” “screening tool” “screening instrument” “screening questionnaire” “screening questionnaires” “screening interview” “screening test” OR “screening tests” OR “screening assessment” “screening survey” “diagnostic tool” OR “diagnostic tools” Australia, Oceanic Ancestry Group [mh] aborigin* OR indigenous).

For the international search, the same terms were used, but the following were added: aboriginal, indigenous, “native american” “native canadian” “american indian” inuit* eskimo* Alaskan* “first nations” maori* polynesian* melanesian* Micronesian.

Appendix 2. General acquired communication disorder screening tools/assessments examined

1. Frenchay Aphasia Screening Test	Enderby, Wood, Wade, & Hewer, 1987
2. MAST (Mississippi)	(Nakase-Thompson et al., 2005)
3. Ullevaal Aphasia Screening Test	(Thommessen, Thoresen, Bautz-Holter, & Laake, 1999)
4. Reitan-Indiana Aphasia	Williams & Shane, 1986
5. ScreeLing	Doesborgh et al., 2003
6. Language Screening Test (LAST)	Flamand-Roze et al., 2011
7. Whurr Aphasia Screening Test	Whurr, 2011
8. Cognitive Linguistic Quick Test	Helm-Estabrooks, 2002
9. Aphasia Check list	Kalbe, Reinhold, Brand, Markowitsch, & Kessler, 2005
10. ACE-R language component	Gaber, Parsons, & Gautam, 2011; Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006
11. Communicative Effectiveness Index (CETI)	Lomas et al., 1989
12. Functional Communication Scale	Drummond & Boss, 2004
13. Functional Outcome Questionnaire for Aphasia (FOQ-A)	Glueckauf et al., 2003; Ketterson et al., 2008
14. Communicative Effectiveness Survey	N. J Donovan, Kendall, Rosenbek, & Young, 2008
15. Communication Outcome After Stroke (COAST)	Long, Hesketh, Paszek, Booth, & Bowen, 2008
16. Communication Outcome After Stroke (Carer COAST)	Long, Hesketh, & Bowen, 2009
17. Community Integration Questionnaire for Aphasia	Dalemans, de Witte, Beurskens, van den Heuvel, & Wade, 2010
18. 10 item stroke-aphasia depression questionnaire	Sutcliffe & Lincoln, 1998
19. SAQOL	Hilari et al., 2009
20. Dysarthria speech intelligibility/communication effectiveness	McAuliffe, Carpenter, & Moran, 2010
21. Dysarthria Impact profile 2009	Walshe, Peach, & Miller, 2009
22. Quality of Communication Life scale	Paul et al., 2004
23. BOSS Burden of Stroke Scale	Doyle et al., 2004

Appendix 3. Interview questions for focus groups

- i) Do you use any specific or standard clinical assessment tools at the moment with Aboriginal people, from any area of health?
 - If not, what are the reasons for this?
 - If yes, do you follow the standard protocol or modify it in some way for use with Aboriginal individuals. If modified what are the main ways you modify tools and why do you do this?
- ii) Do you currently see people with ACDs? If yes, do you have some way of assessing communication and the impact of communication or some way of allowing for the communication impairment? Do you have information you give to people about communication impairments/stroke/traumatic brain injury?
- iii) Within your current method of service delivery, in what form would a tool need to be to facilitate your ability to use it day to day?
- iv) Which aspects of everyday communication should be tested in a screening tool in order to identify problems and assess impact?
- v) What specific language features should be noted in the design of the tool e.g. vocabulary, use of questions?
- vi) How is a screening tool best introduced to Indigenous people in hospital or community settings?
- vii) What would make such a tool acceptable and user-friendly for the health professionals using it?

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Figure 1. Overview of process involved in the development of the Aboriginal Communication Assessment After Brain Injury (ACAABI) (foci of current paper highlighted)

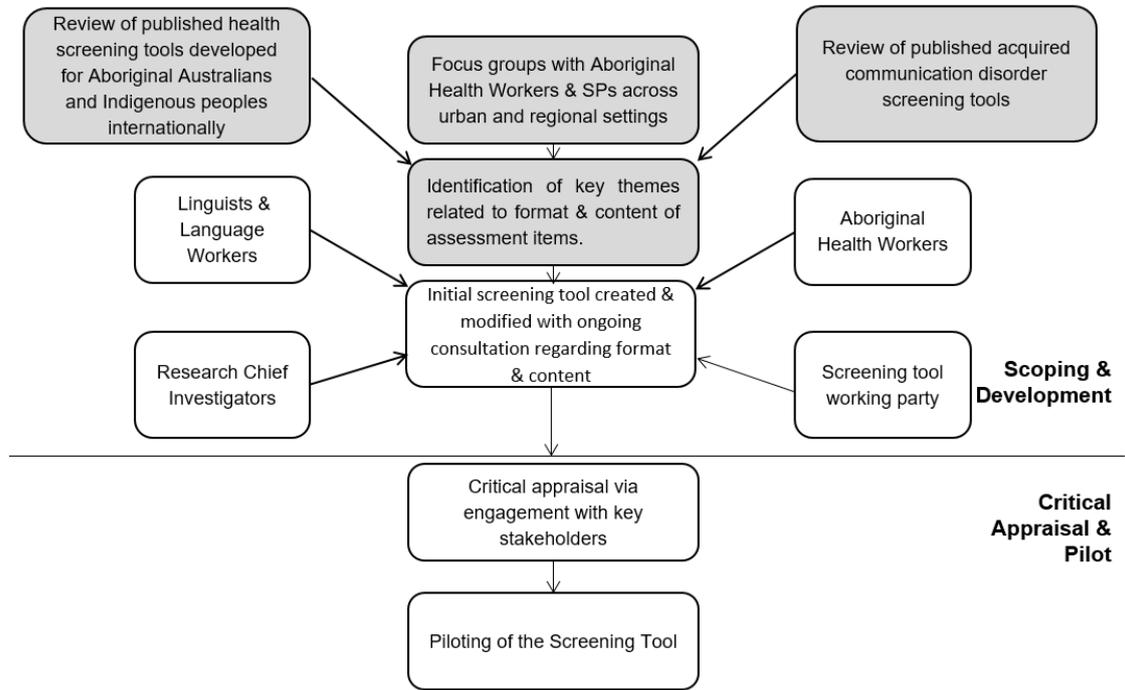


Figure 2. Key principles for screening tool development based on literature review and focus group data

- Incorporation of family perspectives
- Yarning framework: conversational/informal style
- Questions should be asked so as to make them flow logically
- An over-reliance on use of questions may result in inaccurate information being obtained
- Some structured tasks e.g. naming may assist with the assessment of individuals with severely impaired communication
- Vocabulary and pictures familiar to Aboriginal people with ACD – preferably need to be localised
- Items not to be patronising e.g. boomerang; kangaroo
- Quick/not too many items so as to be practical for Aboriginal Health Workers
- To be administered by an Aboriginal person
- Time needed to develop trust between person administering test & the person with an ACD
- Awareness that the person with ACD may not be familiar with testing situation & may not see relevance of naming, picture description/ explanations required
- Awareness of vulnerability of the person with ACD to ‘judgements’ regarding communication style
- Awareness of varying degrees of literacy
- Translatable
- Education on brain injury to be incorporated into assessment process
- Age, status, gender must be taken into account when planning administration of test/who is involved
- Sensitivity needs to be shown when asking questions on certain topics
- Items related to pragmatic/cognitive communication issues be given special consideration due to different cross-cultural communication ‘rules’