Spreading the word about communication difficulties after stroke and traumatic brain injury in Indigenous Australians:

An introduction to Missing Voices.

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The *Missing Voices* research team

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Voices... words... language... culture... connection... identity
What happens when speech or language is lost/impaired?
Community consequences…

- Loss of language in a verbal-based culture
- Elders of community: “living libraries”
  - (Juli Coffin)
- Issues around cultural security: preserving stories, wisdom and learning
- Important need to help support the communication of people with ACD
Plan for *Spreading the word* presentation

- Background
  - Acquired communication disorder (ACD)
  - Current situation for Aboriginal People following stroke or traumatic brain injury (TBI)
- Missing Voices project and research aims
- Methodological approach
- Where we are so far…
- Where we are aiming…
Types of Communication Problems

- Aphasia
- Cognitive Communication Disorders after Traumatic Brain Injury
- Dysarthria
Aphasia – areas of impairment

- Verbal expression
- Comprehension of language
- Gesture
- Calculation
- Reading
- Writing
Cognitive Communication Disorder

- Difficulty maintaining attention
- Difficulty remembering
- Difficulty managing social situations
- Lack of awareness or insight
- Be inappropriate or unable to cope with complexity
- Talk too much or too little
Dysarthria – speech/intelligibility

- Slurred speech
- Change in voice quality
- Low volume
- Fatigue
- Poor control of intonation
- Slow speech
Stroke & TBI
Almost half the people admitted to hospital with acute stroke have some level of communication difficulty
  • O’Halloran, Worrall & Hickson, 2012
Up to a third of patients with a first-ever stroke will experience aphasia
Up to 25,000 Australians with stroke will have an ACD
approximately 60% of these people still have aphasia at 12 months.
Stroke and TBI for Indigenous Australians

- Incidence rate of stroke for Indigenous Australians up to 3 times higher than for non-Indigenous Australians – felt to be underestimate
  (AIHW, 2008; Katzenellenbogen et al., 2011)

- Indigenous stroke patients aged 18-64 had a threefold chance of dying or being dependent at discharge
  (Kilkenny et al., 2012)

- Traumatic brain injury (TBI) has an incidence rate of 2.3% compared to 0.7% in the non-Indigenous population and is up to 21 times higher when caused by assault.
  (Gauld, Smith & Bowen, 2009; Jamieson, Harrison & Berry, 2008)
Age-sex pyramid of incident stroke cases, by Indigenous status: Western Australia 1997-2002

Indigenous

Non-Indigenous

Age-specific incidence of stroke, by Indigenous status: WA 1997-2002

Age-specific rate ratio
3.2  5.7  4.1  2.4

Age-specific rate ratio
3.4  7.4  5.6  3.4

Current situation on rehabilitation experiences

- Very little published
- Indigenous Australians with ACD are:
  - Under-identified
  - Often lost in the system
  - Have low service use
  - Poor follow up

  (Armstrong et al., 2012)
Main issues

- General health issues
- Socio-economic status
- Distance from speech pathology service
- Service ‘not for us’
- Historical reasons
- Language issues
- Lack of knowledge of aphasia
- Service not what people want
  - Appointments, unfamiliar location, therapist gender,
- Cultural attitudes/beliefs
Missing voices project and research aims

- To investigate the extent and impact of ACD in urban and rural Western Australian Indigenous populations following stroke or TBI
- To develop and validate a culturally appropriate communication disorder screening/assessment tool for use by health professionals working with this population
- To explore how Indigenous people, and their family members experience ACDs and rehabilitation services after stroke or TBI
- To understand health professionals’ views of diagnosis, treatment and support for Indigenous people with ACD after stroke or TBI
- To develop potential alternative service delivery models that are accessible and culturally appropriate
Methods

- Analysis of Linked Data
- Analyse Patient Information Record System Data (Communicare or other AMS systems)
- File audits: rural hospital (21), Perth (30), AMS (5 files approx)
- Interviewing:
  - People with ACD and their families
  - Aboriginal Health Professionals
  - Speech pathologists and GPs – Aboriginal/Non-Aboriginal
- Screening tool development:
  - Run focus groups with AHWs to gauge what would be appropriate
  - Validate the tool on 30 people with stroke or TBI
Proposed sites

- Perth
- Geraldton
- Kalgoorlie
- Albany
- The Kimberley
Where we are so far...

- **Screening tool:**
  - Review of screening tools currently available
  - Focus groups run with Aboriginal Health Workers in Perth and Geraldton
  - Development of a draft tool and feedback
- **Forming the Indigenous Reference Group**
- **Speech Pathology Interviews**
- **Liaison with Aboriginal Health Services**
  - Geraldton, Perth, Albany, Kalgoorlie
- **File audits on speech pathology files**
Training of interviewers and capacity building

- Two day training program offered:
  - Exploring ACD
  - Interviewing skills
  - Interviews adapted for people with communication disorders using “supported conversation for aphasia” (SCA) (Kagan, 1998) combined with yarning as a research tool (Bessarab & Ng’andu, 2010)
Interviewer training

- Aboriginal Research Assistants have received training in Geraldton
- Capacity building and awareness-raising amongst health workers in Geraldton
SCA techniques

- **Acknowledgment of competence**
  - implicit through humour, tone of voice, natural gesture
  - explicit – “I know you know”.

- **Revealing competence**
  - ensuring comprehension through the range of supports – writing key words, interactive drawing, resource material etc
  - ensuring the participants can respond – providing yes/no options, extra time, different modality options for response; verifying responses etc

- **Simultaneous use of these techniques to encourage the natural feel and flow of conversation**
Yarning as a research tool
Bessarab & Ng’andu (2010)

- Yarning:
  - Indigenous cultural form of conversation, often informal chat
  - Reciprocal, mutual
  - Transfer of knowledge often through stories
  - Interwoven with cultural and historical understandings

- “Yarning in a semi-structured interview is an informal and relaxed discussion through which both the researcher and participant journey together visiting places and topics of interest relevant to the research study. Yarning is a process that requires the researcher to develop and build a relationship that is accountable to Indigenous people participating in the research.” (p.38)
Where we are aiming…

- Continuing to develop links across all sites
- To start interviews with people with ACD and families over the next few months
- To continue speech pathologist and GP interviews
- Commence AHW interviews
- To analyse the linked data
- Continue file audits – already begun process in Albany and Geraldton
- To pilot the screening tool…
New understandings…

- We are hoping to start the process of:
  - Understanding the stories of Aboriginal people with ACD
  - Using those stories to inform services
  - To enable Aboriginal Health Professionals and others to identify who has an ACD and match them to the right help
  - To work with communities to develop new service models in the light of our findings
  - Raise awareness and building capacity within Aboriginal communities to address ACD
References


