The experiences of Māori with aphasia, their whānau members and speech-language therapists

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Tōmaiora Seminar
15 April 2014
Acknowledgements

This research was supervised by Dr Clare McCann, Prof Linda Worrall, Dr Matire Harwood and Dr Sue Crengle. I acknowledge and thank the people with aphasia and their whānau who participated in this research. The following whānau asked to be acknowledged by name: L Brown, N Brown, Cornwell, Hoto, Nikora, Potaka, Te Miha, Wanakore.

I acknowledge and thank the speech-language therapists who helped with recruitment and who participated in interviews.

I am grateful for The University of Auckland Doctoral Scholarship which funded this research.
Format

• Background
• Methodology
• Overview of the interviews
• Outcome of:
  – Interviews about experiences of aphasia
  – Interviews about speech-language therapy
  – Speech-language therapist interviews
• Overall conclusions
• Postdoctoral research plans
Aphasia

An acquired neurogenic multimodal communication disorder affecting:

- Understanding
- Speaking
- Reading
- Writing

Not caused by intellectual, motor or sensory deficits

Most commonly caused by stroke

https://www.youtube.com/watch?v=khOP2a1zL9s (1.08-2.15)
Aim to Investigate:

• Current knowledge about the experiences of Māori with aphasia and their whānau members

• Perspectives of Māori with aphasia and whānau
  – Experiences of living with aphasia
  – Experiences of speech-language therapy (SLT)

• Perspectives of speech-language therapists (SLTs)
  – Experiences of providing therapy for Māori with aphasia
  – The service they aim to provide
Motivation

• Tertiary hospital stroke unit
• Large number of Māori inpatients
• Few went on to receive SLT as outpatients

Why?

• Is aphasia not a concern for Māori?
  o Unlikely, given recent research where Māori expressed a need for more SLT input

• Are there barriers preventing Māori with aphasia from receiving therapy?
# Treaty of Waitangi Provisions

<table>
<thead>
<tr>
<th>English text</th>
<th>Māori/text</th>
<th>20th century implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Article One</td>
<td>Crown sovereignty</td>
<td>Parliament’s right and authority to govern</td>
</tr>
<tr>
<td>Article Two</td>
<td>Tribal property rights</td>
<td>Tribal right to exercise tino rangatiratanga [Māori control and determination]</td>
</tr>
<tr>
<td>Article Three</td>
<td>Royal protection and citizenship rights</td>
<td>Māori individuals’ right to expect a fair share of society’s benefits</td>
</tr>
</tbody>
</table>

*Taken from Durie (1998)*
Broader historical processes have undoubtedly shaped their immediate circumstances and the support systems and therapeutic options available to them. These in turn defined how they experienced language loss. Equally, their responses to aphasia were shaped by cultural practices and the world views through which they interpreted their lives.

(Legg, 2010, p. 240)
The Literature

Structured review of the literature
- No articles addressing aphasia in Māori
- No articles involving Māori participants stated to have aphasia (McLellan, McCann & Worrall, 2011)

Evidence of a commitment to improving health and disability outcomes for Māori
- The New Zealand Disability Strategy (Minister for Disability Issues, 2001)
- Ngā Pou Rangahau (Health Research Council, 2010)
- He Korowai Oranga (Minister of Health and Associate Minister of Health, 2002)
Methodology – “it’s complicated”

• Ko wai au? Who am I?

• Research about Māori experiences of aphasia should:
  – Be undertaken in a Māori way
  – Benefit Māori whānau
  – Be accessible to speech-language therapists
  – Inform speech-language therapy practice

• Speech-language therapists approx. 2% Māori

• No single qualitative methodology is suitable
Methodology Solution

• Combine two research approaches:
  – Kaupapa Māori Research (KMR)
  – Interpretive Description (ID)
Kaupapa Māori Research (KMR)...

• Strives for Māori self-determination and empowerment (Bishop, 2005; Walker et al., 2006)

• Privileges Māori knowledge and ways of knowing (Smith, 2012)

• Is transformative (Pihama, 2011)

• Is decolonising (Pihama, 2011)
Interpretive Description (ID)

• Undertaken within a discipline (speech-language therapy)

• Acknowledges the existing knowledge within the discipline

• Applied clinical research
  – addresses a clinical need
  – aims for clinically-relevant applicable findings

(Thorne, 2008)
Synergy in Analysis of Kōrero

• KMR
  “How is this research relevant to Māori?”

• ID
  “How is this research useful for a clinician?”

• This study
Both!
Data Collection

Sharing Precious Kōrero

• In depth semi-structured interviews:
  – 11 Māori with aphasia caused by stroke
  – 23 whānau members, nominated by the participants with aphasia
  – 10 speech-language therapists (five managers and five clinicians)
Interviews with Whānau

• Participants decided:
  o where the interview happened
  o who was there

• Supported conversation techniques
  o Written key words
  o Encourage participant to write or gesture
  o Check understanding
  o Give extra time
  o Modify questions, e.g. Yes/no
Interviews with Whānau

Kōrero (talk) about:

The stroke and its impact on communication

The impact of the changed communication on their lives
<table>
<thead>
<tr>
<th>PWA</th>
<th>M/F</th>
<th>Age range</th>
<th>TPO</th>
<th>Lives</th>
<th>Speaks te reo Māori</th>
<th>Whānau interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connie</td>
<td>F</td>
<td>50-59</td>
<td>10+</td>
<td>Urban</td>
<td>No</td>
<td>husband, daughter</td>
</tr>
<tr>
<td>Latimer</td>
<td>M</td>
<td>50-59</td>
<td>&lt;2</td>
<td>Rural</td>
<td>No</td>
<td>no whānau, SLT present</td>
</tr>
<tr>
<td>Christine</td>
<td>F</td>
<td>60-69</td>
<td>2-5</td>
<td>Urban</td>
<td>No</td>
<td>husband</td>
</tr>
<tr>
<td>Margaret</td>
<td>F</td>
<td>60-69</td>
<td>2-5</td>
<td>Urban</td>
<td>No</td>
<td>partner, brother</td>
</tr>
<tr>
<td>Sam</td>
<td>M</td>
<td>60-69</td>
<td>2-5</td>
<td>Rural</td>
<td>No</td>
<td>partner</td>
</tr>
<tr>
<td>Hone</td>
<td>M</td>
<td>60-69</td>
<td>2-5</td>
<td>Rural</td>
<td>Regularly. English and Māori equally affected post-stroke</td>
<td>wife</td>
</tr>
<tr>
<td>Makere</td>
<td>F</td>
<td>70-79</td>
<td>6-9</td>
<td>Urban</td>
<td>Regularly. Māori better than English post-stroke</td>
<td>2 daughters, 1 son</td>
</tr>
<tr>
<td>Bobby</td>
<td>F</td>
<td>70-79</td>
<td>2-5</td>
<td>Rural</td>
<td>First language as a child but not used in adulthood</td>
<td>husband</td>
</tr>
<tr>
<td>Noeline</td>
<td>F</td>
<td>70-79</td>
<td>2-5</td>
<td>Urban</td>
<td>When praying</td>
<td>daughter, son</td>
</tr>
<tr>
<td>Nan</td>
<td>F</td>
<td>70-79</td>
<td>&lt;2</td>
<td>Urban</td>
<td>No</td>
<td>6 daughters, 3 grandchildren</td>
</tr>
<tr>
<td>Jack</td>
<td>M</td>
<td>70-79</td>
<td>&lt;2</td>
<td>Urban</td>
<td>No</td>
<td>wife</td>
</tr>
</tbody>
</table>

PWA = person with aphasia; M/F = male or female; TPO = time post onset of aphasia (years); rural/urban refers to where the participant lives; te reo Māori = the Māori language.

(Modified from: McLellan, McCann, Worrall & Harwood, 2013b)
For Māori, language is precious, and without it ... well we are a bit lost I think. It is just the way the whole world ticks is through language, and singing

Makere’s younger daughter

Talking, articulating with voice is foundational to our peoplehood, to my mother’s Aitanga-a-Hauiti identity. If you have no one to speak and represent one’s peoplehood, then you die

Makere’s older daughter
Aphasia Matters

It’s an **inner wellbeing** ... it’s not the day-to-day, it’s how do they communicate their sense of them

Nan’s daughter

Look, **I’ll do anything**, anything that it’ll take to clear that blockage

Christine’s husband
Sadness and Loss

**Sadness** sort of permeates the whole family in different ways

Makere’s older daughter

She’s having a little *tangi* (cry) over the thing that she wrote before or the thing that she crocheted before or the stuff she can’t finish now

Noeline’s son
It’s not all bad

For us [as] a family I think [it] **brought us all closer**... And we’ve seen a couple that are in the family that we hadn’t seen for ages and that sort of brought them in as well

Nan’s daughter

I think we’ve sort of realised if we’ve got a problem ... **we have to band together** to try and get through it because we’re not necessarily going to be able to deal with it on our own

Connie’s daughter
It’s not all bad

So the conviviality I guess just gets around having a little meal together or a cup of tea and just ah each other’s presence rather than saying anything, you know

Noeline’s son
Four themes in two pairs

Grieving for what is lost

vs

Recognising what we’ve got

It’s hard

vs

Choosing how to respond
“Grieving for what is lost” but “Recognising what we’ve got”

• Grief for what had been lost
• Recognising what remained or had been gained
• Tension between feelings of grief and gratefulness
• Tension within individuals and within whanau
“Grieving for what is lost” but “Recognising what we’ve got”

I would rather go through everything we’ve gone through... all those things that I miss... all those things I gave up are, you know, they’re nothing compared to not having her round

Connie’s daughter
“It’s hard” and “Choosing how to respond”

• It’s hard – negative emotions

• Choosing a response:

I don’t feel like anyone should be sorry for me ‘cos I’ve still got my Mum Connie’s daughter

versus

Is it really necessary to talk? You know, people get born without being able to speak . . . and that’s how I have to look at it Hone’s wife
Experiences of Speech-language Therapy

Worldview

Relationship

Resources

Setting

We’re happy to do the work but we can’t do it alone

Is this as good as it gets?

(McLellan, K., McCann, C., Worrall, L., & Harwood, M., 2013b)
Good Relationships

Christine:
she good, a lady was good to me
Karen
Is that the speech therapist?
Christine
yeah *nods*. Yeah.

“But with ... ah [SLT]’s ... ah ... ah good ah helping me” Jack

“But then that woman come around, the speech therapist, she was so cool man” Noeline’s daughter
Relationship Maintained Attendance
Poor Relationship

Every time you mentioned speech therapists she’d switch off... you’d say “Oh look we’re off to the hospital now we’re gonna see a speech therapist” and she was like “oh, no, let’s go to town”...

Speech therapy at that point in time I think probably needed to focus more on putting her at her ease as opposed to trying to force her to conform to a rigid set of “this is what we’re gonna do”

Makere’s son
“The story was, I think it was about New York and ducks at New York and my Mum, she at the time blurted out with “But I’m from Hauiti and we have shags!” ... You know the context of the story that she had to read and understand wasn’t something that she was remotely interested in at all”

Makere’s younger daughter
Māori World/Pākehā World

You have to jump through all the hoops to get the support, the funding, the professionals to come, and there’s no Māori-ness about it that I notice... Maybe I could tell a speech therapist “you should do this, get some Māori cards” but I don’t know, I don’t know where you draw the line between Māori things and what should happen in a Pākehā world or Westerner world

Makere’s son
SLT Participants

- 10 SLTs (5 clinicians, 5 managers)
- Work experience in DHBs across New Zealand
- Interviewed face-to-face, Skype, phone
- SLTs spoke about:
  - Experiences of providing therapy for Māori with aphasia
  - The service they aim to provide
Experiences of SLTs

SLT Factors

Resources

Ways of working

McLellan (2013)
What’s different about these findings?

• “If we can demonstrate that Māori experience aphasia like everyone else, then there would be no need to change what we’re doing”
  – Risk that the research could be used as evidence that Māori experience aphasia “like everyone else”
  – This could lead to poorer service provision for Māori
Universal experience of aphasia vs impact of societal context

• Some aphasia experiences shared across individuals and cultures, e.g. love, loss
• Differences arise at the societal level
• Cannot separate experiences of aphasia and aphasia therapy from the societal context
Aim of Postdoctoral Research

Design, pilot and evaluate kaupapa Māori interventions that will improve outcomes for Māori with communication disorders post-stroke
## Similar Needs

<table>
<thead>
<tr>
<th>Seeking:</th>
<th>Whānau with aphasia</th>
<th>Speech-language therapists</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information</strong></td>
<td>Info about stroke, communication disorders and SLT role</td>
<td>Training focused on working with Māori whānau</td>
</tr>
<tr>
<td><strong>Guidance</strong></td>
<td>SLT guidance to enable the whānau take responsibility for rehabilitation</td>
<td>Māori colleagues to guide their work with Māori whānau</td>
</tr>
<tr>
<td><strong>Appropriate therapy resources</strong></td>
<td>Language therapy resources and setting that reflect their world view and identity</td>
<td>Language therapy resources and setting that reflect patients’ world view and identity</td>
</tr>
<tr>
<td><strong>Culturally-safe interactions</strong></td>
<td>Culturally-safe interactions with healthcare professionals</td>
<td>A workplace culture that allows time to practise in a culturally-safe manner</td>
</tr>
</tbody>
</table>
Dual approach

• Material specific to Māori with stroke that provides information, health literacy and self-directed communication rehabilitation

• Training for SLTs to increase their cultural safety and awareness and further their understanding of the issues facing whānau with stroke-related communication disorders
References 1


References 2

References 3


Woven mat background image copied from: http://bahay-kubo.org/?attachment_id=1226