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

Karen Marie McLellan

A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy in Speech Science
The University of Auckland, 2013.
Abstract

The aim of this kaupapa Māori thesis was to describe and analyse experiences of aphasia and aphasia therapy for Māori with aphasia and their whānau members. This was explored from the perspectives of speech-language therapists (SLTs), Māori with aphasia and their whānau members. With disparities for Māori in stroke incidence and outcomes, and worse outcomes for people with aphasia compared to other stroke survivors, investigations into aphasia and its rehabilitation are important for this population.

The qualitative methodology of interpretive description was incorporated within the kaupapa Māori research framework. This novel combination was critical to the research, ensuring it was decolonising and transformative, while acknowledging the role of the discipline of SLT.

Interviews were conducted with 11 Māori with aphasia and their nominated whānau members, and 10 SLTs across New Zealand (five managers and five clinicians). Participants with aphasia and whānau members described a diverse range of experiences. Aphasia can bring many changes in roles and relationships, thus having a profound effect on whānau. Despite difficulties, whānau can actively manage their situation and support the person with aphasia to participate in their whānau and community. Speaking about their experiences of SLT, participants demonstrated that a strong therapeutic relationship is vitally important. The SLT’s appreciation of the world view of the person with aphasia and whānau, the setting of the therapy and the therapy resources all contribute to the success of the relationship, and therefore therapy.

From the SLT perspective, the service provided for Māori with aphasia was determined by individual factors specific to the SLT, the workplace culture and manner of service delivery, and human and non-human resources. These findings revealed that SLTs recognise the need to provide culturally safe services for Māori with aphasia but face many barriers in this.

Together, these findings reveal the impact of the cultural and societal context on Māori experiences of aphasia and language therapy. In describing the experiences of Māori with aphasia, from the perspectives of people with aphasia, whānau members, and SLTs, this thesis lays the foundation for future interventional research on this important issue.
Acknowledgements

When I read a thesis I always start by reading the acknowledgements section. I do this because it tells me a lot about the author and their research journey. As you read these acknowledgements I hope you see that, while I have the privilege to putting my name to this thesis, many people have contributed greatly to it.

First I acknowledge and thank God, the giver of life and infinite love.

Second I acknowledge and thank the people with aphasia and their whānau who inspired this research, and those who gave their precious kōrero in the hope that it would help others in their situation. The following whānau asked to be acknowledged by name: L Brown, N Brown, Cornwell, Hoto, Nikora, Potaka, Te Miha, Wanakore. Special thanks to Whaea Makere, Tumau, Linda, and Raewyn Nikora. Whaea Makere and Tumau contributed so much to this research. I am sorry that they are not here to see the end result.

I also acknowledge and thank the SLTs who recommended participants with aphasia or participated in interviews themselves.

I am grateful to my supervisory team of Dr Clare McCann, Prof Linda Worrall, Dr Sue Crengle and Dr Matire Harwood. Clare, you have been a fantastic academic supervisor and life mentor since the day I started MSLTPrac. Linda, thank you for sharing your connections and wealth of knowledge. The project has become something very different to that which Clare and Linda initially agreed to supervise, and I am grateful to them for coming with me on the journey. Sue and Matire, thank you for seeing a kaupapa Māori researcher in the nervous young woman who contacted you about doing some aphasia research.

Whaea Te Kaanga Skipper, kuia and leader of the rangahau whānau. Thank you for gently sharing your wisdom and life experience. Pikihuia Pomare, thank you for your contribution to the rangahau whānau and helping me get the project up and running.

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I acknowledge my whānau. Thank you Mum and Dad for your constant support of “us kids”, and Turi and Paula Ngatai for helping me to get started with the PhD.

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Diversity of participants

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Glossary

Aotearoa  New Zealand
Āhua  Presence, being, identity
Aroha ki te tangata  A respect for people
Au  I, me
Awa  River
hā a koro ma, a kui ma  The ‘breath of life’ from forbears
Hapū  Sub-tribe
Hauiti  The geographic centre of the tribal group Te Aitanga-a-Hauiti, in Tolaga Bay on the East coast of the North Island of New Zealand
He ngākau pai  A good heart
He wairua pai  A good spirit
Hinengaro  The mind
Iwi  Tribe
Kai  Food, to eat
Kaikaranga  Woman who calls visitors onto the marae
Kaitiaki  Caretaker
Kanohi kitea  The seen face
Kanohi ki te kanohi  Face to face
Karakia  Prayer, incantation
Karanga  The ceremonial call on a marae
Kaua e takahia te mana o te tangata  Do not trample over the mana of people
Kaumatua  An elder
Kaumātua  Elders
Kaupapa Māori  Māori ideology
Kauwhau  Moralistic tale
Kāwanatanga  Government
Kia mahaki  Don’t flaunt your knowledge
Kia tupato  Be cautious
Kohanga reo  Māori immersion pre-school
Kōrero  Narrative, talk, to talk
Kuia  Female elder
Kura kaupapa Māori  Māori immersion primary school
Kūri  Dog
Māmā  Mother
Mana  Prestige, dignity, strength
Mana ake  Uniqueness in this context
Manaaki ki te tangata  Share and host people, be generous
Manaakitanga  Hospitality
Māori  The Indigenous peoples of New Zealand
<table>
<thead>
<tr>
<th>Term</th>
<th>Translation</th>
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<tbody>
<tr>
<td>Marae</td>
<td>Traditional meeting place</td>
</tr>
<tr>
<td>Mate</td>
<td>Sickness, death, problem</td>
</tr>
<tr>
<td>Maunga</td>
<td>Mountain</td>
</tr>
<tr>
<td>Mauri</td>
<td>Life force, life principle, ethos</td>
</tr>
<tr>
<td>Mihi</td>
<td>Greeting, to greet</td>
</tr>
<tr>
<td>Moana</td>
<td>Body of water</td>
</tr>
<tr>
<td>Moteatea</td>
<td>Poetry</td>
</tr>
<tr>
<td>Pākehā</td>
<td>Non-Māori, usually used to refer to New Zealand Europeans</td>
</tr>
<tr>
<td>Pakiwaitara</td>
<td>Legend</td>
</tr>
<tr>
<td>Pāpā</td>
<td>Father</td>
</tr>
<tr>
<td>Pōwhiri</td>
<td>A welcoming ceremony</td>
</tr>
<tr>
<td>Rangahau whānau</td>
<td>Literally research family. Research advisory group</td>
</tr>
<tr>
<td>Taha hinengaro</td>
<td>The mental side</td>
</tr>
<tr>
<td>Taha tinana</td>
<td>The physical side</td>
</tr>
<tr>
<td>Taha wairua</td>
<td>The spiritual side</td>
</tr>
<tr>
<td>Taha whānau</td>
<td>The (extended) family side</td>
</tr>
<tr>
<td>Takawaenga</td>
<td>Liaison officer, intermediary</td>
</tr>
<tr>
<td>Tangata whenua</td>
<td>The people of the land, refers to the Indigenous status of Māori in New Zealand</td>
</tr>
<tr>
<td>Tangi</td>
<td>Funeral, to cry</td>
</tr>
<tr>
<td>Taonga</td>
<td>Property, treasure</td>
</tr>
<tr>
<td>Te Aitanga-a-Hauiti</td>
<td>A tribal group from Tolaga Bay on the East coast of the North Island of New Zealand</td>
</tr>
<tr>
<td>Te Ao Māori</td>
<td>The Māori world</td>
</tr>
<tr>
<td>Te reo Māori, te reo</td>
<td>The Māori language</td>
</tr>
<tr>
<td>Te Whare Tapa Whā</td>
<td>Literally the house with four walls. A Māori model of health</td>
</tr>
<tr>
<td>Te wheke</td>
<td>Literally the octopus, A Māori model of health</td>
</tr>
<tr>
<td>Tikanga</td>
<td>Customs, correct practice</td>
</tr>
<tr>
<td>Tino rangatiratanga</td>
<td>Absolute sovereignty, self-determination</td>
</tr>
<tr>
<td>Titiro, whakarongo . . . Kōrero</td>
<td>Look, listen . . . Speak</td>
</tr>
<tr>
<td>Tupuna</td>
<td>Ancestor</td>
</tr>
<tr>
<td>Tūpuna</td>
<td>Ancestors</td>
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<tr>
<td>Waiaata</td>
<td>Song</td>
</tr>
<tr>
<td>Wairua</td>
<td>Spirit</td>
</tr>
<tr>
<td>Wairuatanga</td>
<td>Spirituality</td>
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<tr>
<td>Waka</td>
<td>Canoe</td>
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<tr>
<td>Wānanga</td>
<td>Seminar</td>
</tr>
<tr>
<td>Whaea</td>
<td>Mother. Used as a term of respect for female elders</td>
</tr>
<tr>
<td>Whakaaro</td>
<td>Thoughts, opinions, feelings</td>
</tr>
<tr>
<td>Whakamā</td>
<td>Shy, embarrassed, loss of mana</td>
</tr>
<tr>
<td>Whakapapa</td>
<td>Genealogy</td>
</tr>
<tr>
<td>Whakawhanaungatanga</td>
<td>A process of establishing relationships</td>
</tr>
<tr>
<td>Whānau</td>
<td>(Extended) family</td>
</tr>
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<td>------------</td>
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</tr>
<tr>
<td>Whanaungatanga</td>
<td>Relationship, group dynamics</td>
</tr>
<tr>
<td>Whatumanawa</td>
<td>The emotional aspect</td>
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## List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CCRE</td>
<td>Centre for Clinical Research Excellence in Aphasia Rehabilitation</td>
</tr>
<tr>
<td>DHB</td>
<td>District health board</td>
</tr>
<tr>
<td>HKO</td>
<td><em>He Korowai Oranga: Māori Health Strategy</em></td>
</tr>
<tr>
<td>ICF</td>
<td>World Health Organization’s International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ID</td>
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</tr>
<tr>
<td>KMR</td>
<td>Kaupapa Māori research</td>
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<td>NPR</td>
<td><em>Ngā Pou Rangahau</em></td>
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<td>NZDS</td>
<td><em>New Zealand Disability Strategy</em></td>
</tr>
<tr>
<td>NZSTA</td>
<td>New Zealand Speech-language Therapists’ Association</td>
</tr>
<tr>
<td>PD</td>
<td>Professional development</td>
</tr>
<tr>
<td>PWA</td>
<td>Person with aphasia</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
</tr>
<tr>
<td>SLT</td>
<td>Speech-language therapist or speech-language therapy</td>
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Extent of contribution by PhD candidate (%): 85

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**Chapter 5:**
McLellan, K.M., McCann, C.M., Worrall, L.E. Harwood, M.L.N. (submitted). "For Māori language is precious, and without it we are a bit lost": Experiences of Māori with aphasia and their whānau

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**Certification by Co-Authors**

The undersigned hereby certify that:
- the above statement correctly reflects the nature and extent of the PhD candidate’s contribution to this work, and the nature of the contribution of each of the co-authors; and
- In cases where the PhD candidate was the lead author of the work that the candidate wrote the text.

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Chapter 1: Introduction

This thesis explores experiences of aphasia and speech-language therapy (SLT) from the perspectives of Māori with aphasia, their whānau members and speech-language therapists (SLTs). As kaupapa Māori research (KMR), this introductory chapter begins with the personal context that shaped the development of the research. This is followed by background information about the Treaty of Waitangi and its relationship to Māori health, information about Māori and stroke, and an explanation of aphasia. Details of the context of SLT in New Zealand are then provided. Having given the background for the research, the aims, methodologies and significance of the research are then outlined. Finally, an overview of the thesis content and format is provided.

Author’s voice

The body of this thesis consists of articles that have been published, submitted, or are in preparation for publication in academic journals. As such, it is written in the style required by those journals – the first person active voice. Because the articles were co-authored, the pronoun “we” is used. The personal reflections in Chapter 1 (Introduction) and Chapter 7 (Conclusion) were written specifically for the thesis by an individual student so the singular pronoun “I” is used in those sections.

Personal context

Ko Mataatua te waka
Ko Tauranga te moana
Ko Opepe te awa
Ko Mauau, ko Tarakeha ngā maunga
Ko Ngaiterangi, ko Whakatōhea, ko Pākehā ngā iwi
Ko Tauwhao, ko Ngai Tamahaua ngā hapū
Ko Opape te marae
Ko Colin McLellan tōku pāpā
Ko Joan Moroney tōku māmā
Ko Huihana Hopa Te Arawaere tōku tupuna
Ko Karen McLellan au

There are two stories here – the story of this thesis and the story of my Māori identity. In many ways they are the same story, although the story of my identity started long before the story of the thesis.

I have always known that I have Māori ancestry. For a long time I was quietly proud of it, but I did not feel “Māori enough” to claim it. As I reflect on that now I can see that my
thinking was a result of living in a colonised society and coming through a colonising education system. I can also see that my tūpuna have gently encouraged me throughout my life, and put people in my path to encourage me on my journey as a Māori woman.

My most salient memory of being Māori during my childhood and teenage years comes from when I briefly attended te reo classes at high school. One day I asked a question in the class and the teacher replied “you Pākehā students don’t need to know that”. She then turned away from me and said “you Māori students need to know this”. My 13-year-old self thought “I’m not going to tell her I’m Māori. If I’m not welcome here as I am then I don’t want to be here”. I stopped taking the class, but I continued to acknowledge my Māori heritage.

Many years later I began my first job as an SLT, at Waikato Hospital. That’s where the story of the thesis joins the story of my Māori identity. At Waikato I worked with many wonderful Māori whānau, and I saw first-hand the impact stroke had on them. It is one thing to read the statistics about Māori and cardiovascular diseases, but it is something else to walk through a hospital ward and see the statistics reflected in the faces in front of you. Shortly after starting work at Waikato I met George Smiler, one of the kaitiaki Māori. George taught me about whakawhanaungatanga and encouraged me to share my whakapapa with Māori patients. I had been keeping quiet about my whakapapa because I did not feel Māori enough to claim it. With George’s encouragement I began to see the importance of whakapapa in whakawhanaungatanga, and at every turn I found acceptance as Māori.

During my time at Waikato I noticed that we SLTs saw many Māori inpatients but few Māori outpatients. I would speak to all my patients before they were discharged from hospital and, for those who needed it, I would offer for them to continue with SLT as an outpatient. I observed that most of the Māori patients would either politely decline or they would accept the offer but not turn up to the appointment. I wondered why. It seemed to me that there were two possibilities. Either their communication disorder was not a problem for them so they had no need for therapy, or we were not offering or providing therapy in the right way. If it were the latter, we needed to look seriously at the service we were providing.

After two years at Waikato I decided to begin studying for a PhD. I needed a scholarship. As I filled in the University of Auckland Doctoral Scholarship form I got to the part where it asks if you are Māori. Māori students were then asked to state their whakapapa and have the form endorsed by the appropriate person from their iwi. That was a challenge for me. I was
not in contact with anyone from my iwi, so why would anyone vouch for me? My Māori whakapapa is on my father’s side but my mother’s cousin is married to Turi Ngatai from one of Dad’s iwi, Ngaiterangi. So with the help of my mother and her mother I arranged to visit Turi, introduce myself, tell him about my plans, and see what happened next. Turi was very supportive of my study plans, and accepting of me as Māori. He did more than endorse my scholarship application, he made me feel worthy of a Māori identity.

Scholarship in hand, I moved to Auckland and began the PhD study, with Dr Clare McCann as my supervisor and mentor. Both wanting to do research in aphasiology, we discussed possible topics at great length and finally came up with an idea for a study about quality of life in people with aphasia. Professor Linda Worrall from The University of Queensland agreed to be a co-supervisor. However, even after the research proposal had been accepted, I had a nagging feeling that there was something else I should be doing. What about all the Māori patients I had seen in the stroke ward? What was quality of life like for them? Does quality of life mean different things in different cultures? I knew that I had to include Māori in this study in some way. I contacted Dr Sue Crengle in Te Kupenga Hauora Māori and, to my surprise, she agreed to meet me. Sue introduced me to Dr Matire Harwood. We talked about the research plan and, I will never know how, but by the time I left the room I had agreed to make the research entirely about Māori experiences of aphasia and to undertake it within a KMR framework. I did not even know what kaupapa Māori was. The way I see it, I did not choose this topic, the topic chose me. I have to think that my tūpuna had a hand in that. Shortly after our first meeting Sue was signed up as a supervisor and Matire a member of my rangahau whānau.

Around this time I received an email from the co-ordinator of the Māori and Pacific Psychology Research Group. I had never thought of attending a Māori student group before, but when I received the email I decided to go along. I admit that one of my reasons for attending was a feeling of obligation, since I had received a scholarship as a Māori PhD student. I found the group to be very welcoming and very affirming of me as a Māori student. At the time I was surprised that no-one ever questioned my Māori identity. Now I understand why. Fellow Māori have never questioned my Māori identity. I have felt welcomed and accepted as I am, and encouraged to grow. In contrast, Pākehā frequently question me. “Are you Māori? What percentage are you?” I have learnt to explain that yes, I am Māori, as well as being Pākehā, and then add that blood quantum is not a Māori concept and Māori do not use that way of identifying people.
Once Sue had accepted me as her student and I was committed to undertaking KMR, I had to learn what that means. It has been a long journey so far, and I expect the journey will never end. As I began my quest to learn about KMR I quickly learnt that identity is integral, and a researcher must be grounded in who s/he is. This meant that an important part of my learning about KMR would involve working out my own identity. The story of this thesis is the story of me beginning to do just that. It is the story of finding my place as a Māori woman and kaupapa Māori researcher.

The Treaty of Waitangi and Māori health

The rationale for this thesis ultimately comes from the Treaty of Waitangi and its relationship to Māori health. Orange (2013) described the events leading up to the signing of the Treaty of Waitangi. In 1769, when James Cook came to New Zealand, the country was made up of independent iwi (tribes), with no central governing system. In the 1770s-1830s Europeans arrived, mainly as temporary visitors, with some traders and missionaries staying on a more permanent basis. In this early period Māori and Europeans were interdependent in trade and fostered good relations. In the late 1830s, when more Europeans starting coming to settle in New Zealand and trying to buy land, the interdependent relationship started to break down. Traders began to feel insecure and called for protection of better trade conditions. In 1833 the Colonial Office in London appointed James Busby as “British Resident” in New Zealand but he had no way to enforce his authority. European settlers who committed crimes were not subject to British law, and New Zealand had no central government. In addition, there was other foreign interest in New Zealand. Following an attempt by France to set up an independent state in Hokianga, the Declaration of the Independence of New Zealand was signed by 34 northern chiefs in 1835. In this Declaration, the British government recognised New Zealand’s independence and afforded the protection of the British Crown.

In 1839 more European settlers began arriving under the “New Zealand Company”. The British government wished to make New Zealand a British colony but, having already signed the Declaration of Independence, they could not do so without the consent of the chiefs. In 1839 William Hobson was given the task of attempting to sign a treaty with Māori chiefs giving Britain sovereignty over all or part of New Zealand. The intended purpose of this treaty would be to protect Māori rights and control the current settlers and expected European emigrants. As a result, the Treaty of Waitangi was signed in 1840, by representatives of the British Crown and more than 500 Māori chiefs. Not all chiefs signed
the Treaty, with some deciding not to sign and others not having the opportunity to sign (Orange, 2013).

Differences between the Māori text and the English text led to different understandings of the meaning and implications of the Treaty (Orange, 1997). In the first two articles of the English text Māori ceded “sovereignty” to the British Crown but retained “full exclusive and undisturbed possession” of land, forests, fisheries and other property. In the first two articles of the te reo Māori (Māori language) text the chiefs ceded “government” (kāwanatanga) of their lands but retained “entire supremacy” (tino rangatiratanga) of land, settlements and all personal property (taonga) (English translation from Coleman, 1865). Article three of both texts states that the Crown gave Māori protection and the same rights as British subjects. Durie (1998, p. 84) interpreted the twentieth-century implications of the Treaty of Waitangi as follows:

- Article One: Parliament’s right and authority to govern
- Article Two: Tribal right to exercise tino rangatiratanga
- Article Three: Māori individuals’ right to expect a fair share of society’s benefits

Under Article Two, Māori have the right to exercise tino rangatiratanga. By giving Māori the same rights as British subjects, Article Three entitles Māori to the same standard of health as that enjoyed by non-Māori (Durie, 1998). Current inequities in health status between Māori and non-Māori (Reid & Robson, 2007) demonstrate that Article Three is not yet being fulfilled. Articles Two and Three work together in healthcare. Māori have the right to determine what is important and relevant in healthcare, and how it is best delivered (Article Two) to provide a share of society’s benefit of good health (Article Three).

However, in order to freely exercise tino rangatiratanga, Māori need fair access to other Article Three benefits such as funding for health research and interventions.

The link between the Treaty of Waitangi and Māori health was formalised in 1986 when the Department of Health issued a “circular memorandum” stating:

> For the Department of Health, the Treaty has special significance. Concepts of health are firmly based in Māori culture (which, according to the Treaty, has a right to official recognition and protection) and Māori people have a right to appropriate services – funded through our health system (Department of Health, 1986, p. 2)

This document issued six “challenges” to the development of the New Zealand health system, the first challenge being “that the three articles of the Treaty of Waitangi be
regarded as the foundation for good health in New Zealand” (Department of Health, 1986, p. 2).

The link between the Treaty of Waitangi and health was further emphasised in the New Zealand Public Health and Disability Act 2000. The “Preliminary Provisions” of that Act state that:

In order to recognise and respect the principles of the Treaty of Waitangi, and with a view to improving health outcomes for Maori, Part 3 provides for mechanisms to enable Maori to contribute to decision-making on, and to participate in the delivery of, health and disability services (“New Zealand Public Health and Disability Act 2000,” 2000)

In summary, the Treaty of Waitangi entitles Māori to enjoy standards of health equal to non-Māori and to contribute to the development of appropriate health services. Although these concepts were not explicitly stated in the Treaty, they have been formalised in later government documents. Because the Treaty of Waitangi is the “foundation for good health in New Zealand”, and SLTs are health providers, the Treaty is also the foundation for SLT. Therefore, Māori with stroke and aphasia are entitled to outcomes equal to those of non-Māori, and to contribute to the development of appropriate SLT services.

**Stroke and Māori**

Globally, stroke is the third highest cause of disability-adjusted life years (that is, years of life lived with disability or lost due to early death) (Murray et al., 2012). In addition, stroke is recognised as “a major public health challenge in New Zealand” (Tobias, Cheung, Carter, Anderson, & Feigin, 2007, p. 520). In summarising the stroke-related disparities faced by Māori, Curtis, Harwood, and Riddell (2007) demonstrated that the burden of stroke is not equally distributed in New Zealand. Disparities include stroke incidence, age at first stroke and rehabilitation outcomes. For example, in the years 2006-2008, for adults aged over 35 years, stroke mortality was more than one-and-a-half times higher for Māori than non-Māori (rate ratio 1.68, age-sex-standardised) (Ministry of Health, 2010). Of more interest for the current study is the prevalence of stroke-related disability. In the years 2006-2008, for adults aged over 35 years, Māori were hospitalised with stroke at twice the rate of non-Māori (rate ratio 2.00, age-sex-standardised) (Ministry of Health, 2010). Tobias et al. (2007) estimated the 2001 stroke incidence, prevalence and mortality figures for New Zealand and projected them to 2011. Later figures are not available. They calculated 37,000 stroke survivors in New Zealand in 2001, with almost 7,500 people (approx. 20%) needing daily assistance for
self-care and over 18,600 people (approx. 50%) living with mild to moderate disability. The number of stroke survivors was projected to increase to 45,000-46,500 by 2011, along with a related increase in the number of people living with a stroke-related disability. These stroke disability figures do not comment on any ethnic differences. However, given that Māori experience a higher incidence of stroke than non-Māori, it is to be expected that a greater proportion of Māori than non-Māori will be living with stroke-related disabilities.

Compared to New Zealand Europeans, Māori are on average 14.9 years younger at the time of first stroke (Carter et al., 2006). Stroke at a younger age has a bigger impact on families because of lost ability to work and therefore lost income. This potentially affects both the person with stroke and family members who become carers (Fink, 2006; Moewaka Barnes & Tunks, 1996). In addition, Fink noted that rehabilitation services in New Zealand are less readily available for patients aged under 65 years.

A study by McNaughton, Weatherall, McPherson, Taylor, and Harwood (2002) found that, at discharge from hospital, there was no significant difference in abilities and independence between Māori and New Zealand European stroke survivors. However, at 12 months post-stroke Māori were comparatively more disabled and more likely to be dependent on others. Harwood et al. (2012) addressed this discrepancy in a randomised controlled trial (RCT) promoting self-directed rehabilitation in the first year post-stroke. In their study, trained research assistants delivered “take charge sessions” in which the person with stroke and whānau were assisted to set goals and plan how to achieve them. They found that participating in a “take charge session” significantly improved health-related quality of life and reduced dependence and carer strain. The success of this RCT demonstrates that stroke rehabilitation outcomes can be improved with the provision of suitable intervention.

**Aphasia**

Stroke is the most common cause of aphasia (Goodglass, 1993), which results from approximately 25-30% of strokes (Dickey et al., 2010; Engelter et al., 2006; Kauhanen et al., 2000). Aphasia is a group of neurogenic disorders that affect a person’s ability to use language (Goodglass, 1993). It can affect a person’s ability to understand spoken language, to speak, read and write. The communication difficulties of aphasia are not caused by muscular weakness, paralysis or sensory impairment (poor vision or hearing).

The loss of speech resulting from brain injury has been recorded as early as the fifth century BC, but it was not until the late sixteenth century that language-specific disorders began to
be recognised (Goodglass, 1993). Major advances in understanding of aphasia were made when Broca (in 1861) and Wernicke (in 1874) identified specific language disorders arising from lesions in specific parts of the brain (Goodglass, 1993). These areas are now known as Broca’s area and Wernicke’s area, and the language disorders that arise from lesions to these areas are Broca’s aphasia and Wernicke’s aphasia. Further understanding of aphasia and developments in aphasia therapy came as a result of the Second World War. With a large number of soldiers with combat-related brain injuries, there was an increase in funding for research and to train psychologists and SLTs in aphasia rehabilitation (Goodglass, 1993).

Since Broca in 1861, a number of aphasia classification systems have been created. These are taxonomies that classify aphasias based on the observed pattern of language deficits and strengths. According to McNeil and Copland (2011), the two most common taxonomies are nonfluent versus fluent and the Boston Diagnostic Aphasia Classification System (Goodglass, Kaplan, & Barresi, 2001). Goodglass et al. (2001) described the nonfluent versus fluent classification as distinguishing “two contrasting speech output patterns, representing opposing subtypes of aphasia” (pp. 6-7). Nonfluent aphasias are associated with lesions in the anterior speech area and fluent aphasias more posterior lesions (Goodglass et al., 2001). The terms “nonfluent” and “fluent” refer to the typical number of words used in a breath group. Goodglass et al. (2001) identified that people with nonfluent aphasia rarely use more than three to four words in a breath group while people with fluent aphasia commonly use five or more. They noted that this distinction does not apply to people whose aphasia has improved to the point where they exhibit only mild difficulties. Although the nonfluent/fluent classification is commonly used, there are several problems with it. Goodglass et al. (2001) noted that only 60-70% of aphasia presentations are clearly nonfluent or fluent. McNeil and Copland (2011, p. 42) reported that the criteria for classifying nonfluent versus fluent aphasia are largely undefined and, as such:

The clinical and research use of the fluent and nonfluent aphasia classification is a conceptual step backward and should be discontinued until the construct can be objectified, theoretically justified, empirically validated, found reliable, broadly taught to all relevant disciplines, and found useful clinically for prognosis or some other purpose.

The Boston Diagnostic Aphasia Classification System classifies aphasia syndromes based on eight characteristics – articulatory agility, phrase length, grammatical form, melodic line (prosody), paraphasia in running speech, word finding relative to fluency, sentence
repetition and auditory comprehension (Goodglass et al., 2001, p. 61). Paraphasias are “the production of unintended syllables, words, or phrases during the effort to speak” (Goodglass et al., 2001, p. 9). Each aphasia syndrome exhibits a different pattern of these eight characteristics. In the current study we did not classify the participants into aphasia subtypes or syndromes because we considered such classification to be outside the aims of this study.

Independent of the severity and characteristics of the language disorder, aphasia can have major psychosocial implications for the stroke survivor and their family members. Compared to other stroke survivors, people with aphasia have been shown to be more likely to suffer from depression (Kauhanen et al., 2000), less likely to return to work (Wozniak & Kittner, 2002) and have lower health-related quality of life (Hilari, 2011). In comparison with healthy age-matched peers, people with aphasia have been shown to have smaller social networks, take part in fewer leisure activities and be less satisfied with their activities (Cruice, Worrall, & Hickson, 2006b). In addition, aphasia can negatively impact family relationships (Grawburg, Howe, Worrall, & Scarinci, 2013a; Le Dorze & Brassard, 1995; Michallet, Tétreault, & Le Dorze, 2003). It is therefore not surprising that aphasia has been described as “identity theft” (Shadden, 2005) for both the person with aphasia and their family members. Additional difficulties are caused by aphasia being a little-known condition. A recent study by McCann, Tunnicliffe, and Anderson (2013) surveyed 300 people across New Zealand, including 200 members of the general public and 100 health sector workers. They found that 11% of the general public had heard of aphasia (awareness) and only 1.5% knew what it was (knowledge).

Broadly speaking, there are two approaches to aphasia therapy. The “more traditional approach” (Thompson & Worrall, 2008, p. 3) is impairment-based therapy, which aims to treat the impaired elements of language and restore language function to the fullest extent possible. The second, and later developing approach, is known by many names, including “functional”, “social” and “consequences”. This intervention focuses on reducing the impact of aphasia on the person’s life participation (Thompson & Worrall, 2008). The “consequences” approach to aphasia therapy includes recognition of the psychosocial impact of aphasia. This approach has been influenced by models of disability, including the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001a). In the ICF, the “Body Functions and Structures” that are affected by aphasia are considered alongside the “Activities” and “Participation” that the person with aphasia undertakes. The context of “Environmental
Factors” and “Personal Factors” is recognised. A “consequences” approach to aphasia therapy can target “Activities”, “Participation”, “Environmental Factors” or “Personal Factors”, both directly and indirectly (Thompson & Worrall, 2008). Both the impairment-based approach and the consequences approach aim to improve communication for people with aphasia in their environments. SLTs are encouraged to use a combination of both approaches to meet the individual needs of people with aphasia (Thompson & Worrall, 2008).

**Speech-language therapy – the New Zealand context**

SLTs in New Zealand work with people from birth through to old age who have difficulties with communication or swallowing caused by developmental, congenital and acquired conditions. The largest employer of SLTs in New Zealand is the Ministry of Education, Special Education. The second largest employer is the Ministry of Health, through district health boards (DHBs). Smaller numbers of SLTs are employed by school boards of trustees, private practices, universities and charitable trusts (New Zealand Speech-language Therapists’ Association, personal communication, 2013). All SLTs are qualified to work in health and education, with adults and children. There are three SLT tertiary education programmes in New Zealand. University of Canterbury offers a four year “Bachelor of Speech and Language Pathology with Honours”, Massey University in Albany offers a four year “Bachelor of Speech and Language Therapy” and The University of Auckland offers a two year “Master of Speech Language Therapy Practice”. Graduates of all three programmes meet the required competency-based occupational standards (Speech Pathology Australia, 2011) and therefore are entitled to practise as an SLT in New Zealand.

In New Zealand, SLT is not a registered profession. The New Zealand Speech-language Therapists’ Association (NZSTA) is the professional association body. Membership is voluntary. An SLT’s decision to join the NZSTA, or not, is often influenced by whether their employer will pay or contribute to the membership fee. Many SLTs employed by the Ministry of Education are covered by the primary teachers’ collective agreement (Ministry of Education, 2010-2012). This collective agreement does not specifically state that the employer will pay professional membership fees. Many SLTs employed by the Ministry of Health are covered by the Public Servants’ Association Multi-employer collective agreements for allied health, public health, and technical staff. These documents currently state that the employer will pay professional body membership fees, up to a maximum amount (Public Service Association, 2010-2012a, 2010-2012b).
The number of SLTs in New Zealand is estimated to be 1100-1200. No definitive information about the workforce is available because there is no governing body that collates workforce statistics. The 2006 national census (which is the most recent one available) gives a total of 576 SLTs in New Zealand (Statistics New Zealand, 2007) and the Careers NZ website states that in 2012 there were 552 (Careers NZ, 2013). However, these figures seem to be an underestimation. By the end of 2012, the NZSTA had a membership database of 582 full and provisional members, including part-time and non-practising members. Given that an estimated 50% of SLTs are NZSTA members (NZSTA, personal communication, 2013), 1100-1200 is a more likely total number.

Ideally, the ethnic and socioeconomic characteristics of the clinical workforce should reflect those of the population served (The Royal College of Speech and Language Therapists, 2006). Therefore, the demographics of New Zealand SLTs, and the population they serve, are more relevant than total numbers. Of most relevance to the current study is the clear mismatch between the number of Māori SLTs and the number of Māori patients likely to be requiring their services. Māori make up an estimated 15% of the New Zealand population (Statistics New Zealand, 2012). In 2006 there were 152 SLTs employed by DHBs in New Zealand (114.9 fulltime equivalent staff). Of this group, only three were Māori (2%) (Allied Health Workforce Strategy Group, 2007). In 2012, 2.6% of the NZSTA membership identified as Māori (NZSTA, personal communication, 2013). This means that most Māori with aphasia who receive therapy will receive it from a non-Māori SLT.

In New Zealand, SLT is a self-regulating profession, monitored by the NZSTA. In order to gain accreditation from the NZSTA, the three SLT degree programmes must meet the standards set by the NZSTA Programme Accreditation Committee. The four current standards, documented in the Programme Accreditation Framework 2011 (New Zealand Speech-language Therapists’ Association, 2011), are “The Aotearoa/New Zealand Context”, “Education Programme Structure”, “Clinical Education” and “Academic Education”. Most relevant to the current study is the “Accreditation Standard for the Aotearoa/New Zealand Context”, which includes the content:

That the Programme reflects te Tiriti o Waitangi in its recruitment, curriculum and clinical education practices. This includes recognition of Māori as tangata whenua, and how this and the Tiriti apply to professional practices. The Programme needs to provide students with the best available evidence re. Māori responsiveness, practice, theory and intervention and show how these are woven throughout the Programme (New Zealand Speech-language Therapists’ Association, 2011)
The standard then lists specific requirements and acceptable evidence to demonstrate these.

The *Programme Accreditation Framework 2011* provides significantly more detail about “the New Zealand Context” than the previous 2001 version (New Zealand Speech-language Therapists’ Association Incorporated, 2002). The 2001 Framework stated that “Programmes will demonstrate cognisance of and responsiveness to New Zealand culture and current political and quality initiatives”. It required that programmes demonstrate “adherence to the obligations of the Treaty of Waitangi” and gave brief guidelines for the support of Māori students. Prior to 2002 there was no programme accreditation framework (personal communication, Jo de Seriere 2013).

In late 2012, an NZSTA working party delivered a “clinical issue” titled *Te Tiriti o Waitangi and Clinical Practice*. This series of professional development (PD) teleconferences was attended by over 50 SLTs across New Zealand and abroad (NZSTA, personal communication, 2013). It was followed up with a presentation on the same topic at the national NZSTA PD event in mid-2013. The success of the “clinical issue” and the developments between the 2001 and 2011 programme accreditation frameworks demonstrate that, within the SLT profession in New Zealand, there is a growing recognition of Māori as tangata whenua and of the importance of the Treaty of Waitangi. Exactly how this manifests itself in clinical practice remains to be seen.

**Aims of the research**

The Treaty of Waitangi entitles Māori to enjoy standards of health equal to non-Māori. In addition, it entitles Māori to contribute to the development of health services. The SLT profession in New Zealand has recognised the relevance of the Treaty of Waitangi to professional practice and demonstrated a dedication to being responsive to Māori. In this climate there is a need for research to guide clinical practice. SLT training programmes are required to “provide students with the best available evidence re. Māori responsiveness, practice, theory and intervention” (New Zealand Speech-language Therapists’ Association, 2011). In order to ascertain the “best available evidence” with regard to Māori with aphasia, the primary aim of this thesis was to investigate what is currently known about the experiences of Māori with aphasia and their whānau members. This was achieved with a structured review of the literature, in which evidence gaps were identified. Further research (the second and third aims of the thesis) addressed the gaps in that evidence. The second aim was to explore, from the perspectives of Māori with aphasia and their whānau members,
experiences of aphasia and, more specifically, aphasia therapy. The third aim was to examine, from the perspectives of SLTs, the service SLTs are currently providing for Māori with aphasia and the service they are striving to provide. Before any of this research could be undertaken it was necessary to determine the most appropriate research approach.

**Research approach**

This is a KMR project. A detailed explanation of what this means and why a KMR approach was chosen is provided in Chapter 3. In accordance with KMR (Irwin, 1994) the project was guided by a rangahau whānau, led by a kuia. This group met and approved the research before the project commenced and reconvened several times during the research process. In a final meeting with the researcher, the kuia approved the findings and gave advice for future directions for the research. As discussed above, the current New Zealand SLT workforce is less than 3% Māori. Therefore, to make the research applicable to non-Māori SLTs as well as Māori with aphasia, it was necessary to incorporate a qualitative methodology within the KMR framework. Because there is no published aphasia research using a KMR approach, there was no precedent for this. Background reading suggested that interpretive description (ID) would be an appropriate qualitative methodology to use within a KMR framework. Although KMR and ID come from different paradigms and different world views, both pursue relevant, applicable findings that will make a positive difference in people’s lives. Because of their different backgrounds, each approach emphasises different aspects of the research process. Therefore, at times KMR was more prominent in this research and at others ID was more prominent, as each filled gaps left by the other. When the two approaches conflicted, we chose to allow KMR to overrule ID, as befits Māori research. A detailed explanation of the interaction between KMR and ID is provided in Chapter 3.

**Overview of the thesis**

This thesis is presented as a “thesis with publications”. In accordance with the University of Auckland Guidelines for Including Publications in a Thesis, “the core of the thesis comprises a series of published [and] unpublished research papers” and a “contextual framework and concluding discussion” is provided (Clause 1g). Each chapter is published in a journal, is under peer review for publication in a journal, or is in preparation for submission to a journal. Specific details are provided at the beginning of each chapter. The literature review (Chapter 2) was published in March 2011, more than two years before the
completion of the thesis. As allowed for in Guideline 4, this article has not been updated for the thesis but is included, with permission, as it appeared in the *New Zealand Medical Journal* (McLellan, McCann, & Worrall, 2011). Following publication of the literature review, alerts were set up on Medline for the keywords “aphasia” and “Māori”, and “aphasia” and “indigenous”. This was to ensure we captured any new research published after the literature review. In the two years, these alerts produced only one document – an article about cognitive assessment in Aboriginal Australians, which is not relevant to aphasia research. Although little has changed since March 2011, the small amount of literature that has emerged in the intervening time has been incorporated in the introductory sections at the beginning of each chapter (or article).

The current research is novel. It is the first time that Māori experiences of aphasia have been explored. Therefore, there is no literature specifically addressing this topic. In the absence of any directly-relevant literature, we have drawn on literature about Māori with stroke (not specifically aphasia), Indigenous people with aphasia (not specifically Māori), and cultural, rather than linguistic, perspectives of aphasia (not specifically Māori).

On the topic of Māori and stroke, two further relevant documents have become available since the publication of the literature review – an unpublished thesis titled *Understanding and Improving Stroke Recovery for Māori and Their Whānau* (Harwood, 2012) and an RCT “promoting self-directed rehabilitation to improve quality of life” for Māori with stroke (Harwood et al., 2012). Harwood (2012) provides added rationale for the current study, with participants identifying the need for more SLT input. While Harwood et al. (2012) do not specifically address aphasia, it is evident that people with aphasia were involved in the study because the authors note that the language disorder prevented some participants from completing some of the follow-up measures.

Throughout the world there is very little research with Indigenous peoples with aphasia, a fact highlighted by Armstrong, Hersh, Hayward, Fraser, and Brown (2012) in their pilot study exploring the experiences of three Aboriginal men with aphasia in Western Australia. The study of Armstrong et al. is currently the most comprehensive published study of aphasia in Indigenous peoples. The majority of the SLT literature about “culturally and linguistically diverse” clients (the commonly used terminology) focuses on the linguistic aspects of bilingual aphasia. Contrary to what the terminology promises, it provides minimal comment on cultural aspects of aphasia (e.g. Centeno, 2009; D’Souza, Kay-Raining Bird, & Deacon, 2012). A notable exception is the research of Legg (2010) and
Legg and Penn (2013) who focused on experiences and cultural understandings of aphasia in Khayelitsha, a poor township on the outskirts of Cape Town. Like the research of Armstrong et al. and Legg and Penn, this thesis focuses on cultural rather than linguistic perspectives of aphasia. Approaching the issues from a Māori perspective, this broadens the viewpoint that has previously been taken in aphasiology.

Data presented in this thesis were collected in a series of interviews with two groups of people—Māori with aphasia and their whānau, and SLTs working with Māori with aphasia. Together, these two groups inform a thorough investigation into the experiences of Māori with aphasia and their whānau. By providing comment on aphasia experiences and current clinical practice, from the perspective of both clients and clinicians, the study lays the foundation for future research in which the findings can be used to inform SLT interventions. In addition, a thorough investigation into the methodological challenges of conducting KMR with Māori with aphasia, presents a novel combination of research approaches that has the potential to be used in future clinical research.

**Structure of the thesis**

As the foundational literature review for this research, the aim of Chapter 2 was to identify the current understanding of the experiences of Māori with aphasia and their whānau members. A database search (for which details are provided in Chapter 2) revealed no published articles addressing aphasia in Māori and no research involving Māori stated to have aphasia. It did, however, reveal three government documents showing that this is an area in need of investigation. These documents, which are referred to throughout the thesis, are *Ngā Pou Rangahau* (*NPR*) (the Health Research Council of New Zealand strategic plan for Māori health research 2010-2015) (Health Research Council of New Zealand, 2010), the *New Zealand Disability Strategy* (*NZDS*) (Minister for Disability Issues, 2001), and *He Korowai Oranga* (*HKO*) (Māori health strategy) (Minister of Health and Associate Minister of Health, 2002). The gaps identified in the literature review determined the direction of the subsequent research.

To provide a balanced investigation of the experiences of Māori with aphasia, it is necessary to gain the perspectives of three different groups – Māori with aphasia, members of their whānau and the SLTs who work with them. Details of the participants and the recruitment processes are provided in the relevant chapters. Chapters 4 and 5 explore the findings of in-depth semi-structured interviews with 11 Māori with aphasia and their nominated whānau...
members. Because experiences of aphasia are shaped by culture (Legg, 2010), an understanding of Māori experiences of aphasia will help inform the provision of culturally safe therapy for this group. The combination of KMR and ID was chosen as the most suitable approach for Chapters 4 and 5 to ensure the research is applicable to Māori with aphasia, whānau members and SLTs. This is the first time KMR has been undertaken in aphasiology and the first time KMR has been combined with ID. Before Chapters 4 and 5 can be fully appreciated, it is necessary to understand KMR, ID, and the interaction between them. Therefore, in Chapter 3 we provide an in-depth explanation of KMR and ID, how they work together in theory, and how they worked together in practice. We also discuss the ways in which KMR and ID influenced the research process and interpretation of the results.

In Chapter 4 we explore the broad experiences of Māori with aphasia and their whānau members. Participants spoke about changes in communication following the stroke and how these changes impacted on their relationships, health, spirituality, activities, and family and community roles. Focusing specifically on Māori experiences of aphasia therapy, Chapter 5 provides a more in-depth analysis of some of the data presented in Chapter 4. While describing the current situation, we make preliminary recommendations for ways in which aphasia therapy for Māori could be improved. Therapy experiences are singled out because a critical analysis of this data will provide a foundation on which to base future interventional research.

The research continues with an examination of the role of the SLT for Māori with aphasia, from the perspectives of SLTs and SLT managers (Chapter 6). According to the NZDS, disability services should be “accessible to and culturally appropriate for disabled Māori and their whānau” (Minister for Disability Issues, 2001, p. 25). As a precursor to informing the delivery of such a service, it is necessary to ascertain details of the service currently being provided and SLTs’ concept of what makes a service “accessible” and “culturally appropriate”. Therefore, in Chapter 6 we describe and analyse, from the perspectives of SLTs and SLT managers, current service provision for Māori with aphasia and concepts of ideal service provision. This is achieved through qualitative interviews with 10 SLTs (five managers and five clinicians), working with Māori with aphasia across New Zealand.

Because this study involves clinicians, the majority of whom are not Māori, it employs ID as the methodology. However, because the study fits into the wider KMR project, it is influenced by principles of KMR, as detailed in Chapter 6.
In the concluding chapter we summarise the findings of all previous chapters and discuss the challenges faced in the research. Following this, we bring together the literature, the experiences of SLTs, the general experiences of Māori with aphasia and whānau members, and their specific experiences of aphasia therapy. It is only when they are brought together that it is possible to draw conclusions about aphasia and aphasia therapy provision, and to draw these conclusions from both angles (the perspectives of SLTs and of Māori with aphasia and whānau members). In doing so, the impact of the cultural and societal context becomes clear. We then link back to the literature that was introduced in Chapter 2 and referred to throughout the thesis - NPR (Health Research Council of New Zealand, 2010), NZDS (Minister for Disability Issues, 2001), and HKO (Minister of Health and Associate Minister of Health, 2002) and consider how the research addressed the aims of these documents and the identified knowledge gaps. Having laid the foundation with a thorough description of the experiences of Māori with aphasia, whānau members, and SLTs, we give recommendations for clinical practice and future research, with a focus on intervention. Finally, the thesis concludes as it began, with a personal reflection.

References


Chapter 2: Māori with aphasia: A people without a voice?

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This publication is inserted as published, with the exception of minor edits and formatting changes to maintain consistency throughout the thesis. It is included in the thesis with permission from the *New Zealand Medical Journal*. 
Abstract

Aim: This literature review aimed to investigate whether Māori with aphasia and their whānau are being included in research. A second aim was to identify what, if any, specific outcomes or concerns have been reported. Although the prevalence and incidence of aphasia in the Māori population is unknown, it is likely to be relatively high, given the high rate of stroke among Māori.

Methods: We provide a background to Māori health, stroke, aphasia and rehabilitation. A standard review of the literature was conducted in the online databases PsycINFO, ScienceDirect, PubMed, MEDLINE, CINAHL Plus, and Google Scholar. We searched “Māori” AND “aphasia” and “Māori” AND “dysphasia” as “anywhere in text” and as a keyword with no limits placed on publication dates.

Conclusions: The search revealed no articles that involve Māori with aphasia and none that address aphasia in the Māori population. Four articles involved Māori participants with stroke or a condition linked to communication disorders and specifically addressed either culture or ethnicity in their observations or results. We consider possible explanations for this apparent lack of Māori with aphasia as participants in research, and conclude that the investigation of aphasia in Māori requires an approach that involves Māori with aphasia and their whānau, in a way that is culturally appropriate enabling them to have a voice.
“Aphasia” refers to a collection of language disorders that affect oral and written communication and are caused by damage to the brain, most commonly through stroke (Goodglass, 1993, p. 50). The communication difficulties of aphasia are not the result of poor motor speech function or sensory (vision or hearing) impairment.

Stroke is a major health concern in New Zealand, a fact acknowledged by the New Zealand guideline for management of stroke (Stroke Foundation New Zealand, 2003). The guideline emphasises the need for post-stroke rehabilitation to be culturally appropriate, which in New Zealand’s multicultural society presents a challenge. Those who work with people with aphasia following a stroke face an additional hurdle of ensuring the rehabilitation services are both culturally and linguistically appropriate. This literature review discusses some of the challenges involved in culturally appropriate services for Māori with aphasia.

Curtis, Harwood and Riddell (Curtis et al., 2007) report that 2367 Māori (116.1 per 100,000) were hospitalised with stroke in the years 2003-2005 (latest raw figures available). This compares with 22,227 non-Māori (63.3 per 100,000) hospitalised with stroke in the same period (a rate ratio of 1.84 Māori to non-Māori). Figures vary, but the literature suggests that somewhere between 25-30% of people with stroke have aphasia (Dickey et al., 2010; Engelter et al., 2006; Kauhanen et al., 2000). The variation in the figures in these studies may be attributable to methodology (in particular the timing of data collection), the criteria used to diagnose aphasia, and sample sizes. Given Curtis, Harwood and Riddell’s figure of 116.1 per 100,000 Māori hospitalised following a stroke in conjunction with an estimated 25-30% of people with stroke having aphasia, we can therefore approximate the incidence of aphasia in the Māori population to be 600-700 for the period 2003-2005, or just over 200 per year. While possible to calculate, the actual prevalence of aphasia in the Māori population is currently unknown. However, because Māori have a higher incidence of stroke than non-Māori it is likely that the prevalence of aphasia is higher among Māori compared with non-Māori.

For people who have aphasia, the speech language therapist is a key member of the allied health team. In New Zealand, DHBs are the primary provider of speech language therapy services for inpatients, outpatients and/or in community settings. It can be problematic to obtain statistics on the number of Māori receiving speech language therapy for aphasia. There are legal requirements for overt equality in the provision of health services however, the reality for many speech language therapy clinics is not so clear-cut. While all New Zealanders ought to have access to the public health service, it has been observed that
relatively small numbers of Māori with aphasia are receiving input. In another population
that receives speech language therapy (adults with intellectual disability), the National
Advisory Committee on Health and Disability (2003) has reported that Māori adults and
service providers had difficulty accessing communication support. Difficulty accessing
information and support has also been reported by families of Māori children admitted to
hospital (Arlidge et al., 2009).

The context for addressing aphasia in Māori is significant and includes the NZDS, the
Health Research Council of New Zealand strategic plan for Māori health research (NPR),
Māori health models, the role of communication in Māori culture, and the Ministry of
Health’s Māori health strategy (HKO).

**New Zealand Disability Strategy**
The vision of the NZDS (Minister for Disability Issues, 2001) is “a fully inclusive society”.
Of particular relevance, Objective 11 – Promote participation of disabled Māori – behoves
us to examine current service provision to Māori with aphasia (both in the literature and in
clinical practice). Within this objective, two of the seven action points are pertinent to
speech language therapy services. These are: “Establish more disability support services
designed and provided by Māori for Māori” and “Ensure mainstream providers of disability
services are accessible to and culturally appropriate for disabled Māori and their whānau”.
In a qualitative study by Wiley (2009), some Māori receiving disability services felt that
their Māori world view was expected to change in order to fit in with a non-Māori style of
service provision (Wiley, 2009). Additionally, their caregivers identified that increased
well-being for the entire family came through enabling the family member with a disability
to participate in family life. Although Wiley’s study did not include people with aphasia
(personal communication, Wiley 2010) this finding is still likely to be relevant to Māori
with aphasia.

**Ngā Pou Rangahau**
*NPR* (Health Research Council of New Zealand, 2010) is the name given to the Health
Research Council’s strategic plan for Māori health research 2010-2015. Its six goals each
have several objectives. The goal of “Transforming Māori health research knowledge and
practice” includes an objective “to build an evidence base which contributes to improved
Māori health outcomes” and the goal “Translating research into Māori health gains”
includes the objective “to build a research evidence base which can be effectively translated
into improved health outcomes for Māori”. Therefore, we were motivated to review the
literature in order to discover the current evidence base for the treatment of aphasia in Māori, how speech language services are currently responding to the Disability Strategy objectives in general and how they are providing for Māori with aphasia in the particular.

**Māori health models**

A contemporary Māori world view has a holistic perspective of health, as demonstrated by *Te Whare Tapa Whā* (Durie, 1998). In this model the health of an individual is likened to a house with four walls – taha wairua (spiritual), taha hinengaro (mental), taha tinana (physical), and taha whānau (extended family). These four dimensions of health interact and all are required for overall health and wellbeing. Taha hinengaro and taha whānau place particular importance on communication – both as a means of expressing one’s thoughts and feelings (the division between these two is not as distinct as in Western thinking (Durie, 1998)) and communication as important for interacting and being part of a group.

Another model is *Te Wheke* (Pere, 1984), in which the health of the whānau is likened to an octopus. The head of the octopus represents the whānau, with the eyes representing the health and wellbeing of the individuals and the collective. Each tentacle represents a dimension of health and wellbeing. The tentacles are intertwined as the dimensions merge, and all help sustain the whole. The eight elements of *Te Wheke* are wairuatanga (spirituality), hinengaro (the mind), taha tinana (the physical side), whanaungatanga (the extended family, group dynamics), mauri (life principle, ethos), mana ake (uniqueness in this context), hā a koro ma, a kui ma (the ‘breath of life’ from forbears), and whatumanawa (the emotional aspect). Language and interaction feature throughout *Te Wheke* and are specifically mentioned in the areas of wairuatanga, whanaungatanga, mauri, and whatumanawa. Wairuatanga includes the belief that language and a unique identity are given to each person by the Creator. Mauri acknowledges the mauri of the Māori language among other things and its importance for the welfare of the family unit. Whanaungatanga includes the expectation of positive interactions between families, and whatumanawa the expectation of emotional involvement and interaction.

**Communication in Māori culture**

Metge and Kinloch (1978) outlined the importance of communication within Maori tradition. Bishop (1996) further illustrated this when he described how, as an oral culture, language (particularly storytelling) is very important for Māori. Traditionally, knowledge was passed on through narratives in waiata (song), moteatea (poetry), pakiwaitara (legend), kauwhau (moralistic tale), and whakapapa (geneology). In these narratives the mana of the
storyteller was in the delivery of the story as much as the story itself. On the other hand, (Durie, 1998, p. 71) observes that “Māori may be more impressed by the unspoken signals conveyed through subtle gesture, eye movement, or bland expression, and in some situations regard words as superfluous, even demeaning”. These two examples suggest that for Māori, words are important but communication encompasses more than just words. We know that language is important not only for expressing thoughts and emotions, but for understanding ourselves and our society and demonstrating personal identity and affiliation with a group, while recognising that non-verbal communication varies between cultural groups (Crystal, 1997). Given that language is so fundamental to who we are, and so intertwined with culture, it is important that speech language therapy services recognise the cultural implications of communication when working with Māori with aphasia. It has long been recognised that aphasia has an impact on the entire family, not just the individual with aphasia (Währborg, 1989). As part of Te Pūmanawa Hauora’s Oranga Kaumatua study, Waldon (2004) reported the results of a survey in which over 400 older Māori spoke about their perceptions of health. Respondents identified their role of nurturing the culture and passing it on to members of their community. Knowledge of the community and being accepted by others were important factors for older Māori to be able to participate in Māori society. Older Māori also reported close whānau relationships and reciprocity contributing to intergenerational understanding. Compared to their peers without aphasia, older people with aphasia have been shown to engage in less storytelling and have limited reflection and expression of their ideas and opinions in conversation (Davidson, Worrall, & Hickson, 2003). They have also been shown to have smaller social networks and fewer friends (Davidson, Howe, Worrall, Hickson, & Togher, 2008). As a consequence of their language impairment, older Māori with aphasia are likely to have difficulty with passing on cultural knowledge to the community and may find reduced reciprocity in family relationships.

**He Korowai Oranga**

The Treaty of Waitangi is considered to be New Zealand’s founding document (Orange). Durie (2001, p. 54) suggests that “the continuing disparities in standards of health between Māori and non-Māori are clear indicators that much remains to be done” in order to fulfil the obligations of the third article of the Treaty (which affords Māori state protection and the rights of British subjects). In line with the Treaty Principles of Partnership, Participation, and Protection (The Royal Commission on Social Policy, 1988), *HKO* (Minister of Health and Associate Minister of Health, 2002) supports the Māori holistic approach to health and wellness and aims to support Māori as they take control to improve their own health.
Partnership involves working with Māori communities to improve health services and health outcomes for Māori. Participation involves Māori at all stages from decision-making through to delivery of services. Protection addresses health outcomes so that Māori enjoy the same health status as non-Māori and seeks to safeguard Māori cultural values and practices (Minister of Health and Associate Minister of Health, 2002). Linked to the Māori view of health and Treaty Principles, HKO seeks the following outcomes: Whānau experience physical, spiritual, mental and emotional health and have control over their own destinies; whānau members live longer and enjoy a better quality of life; whānau members (including those with disabilities) participate in te ao Māori and wider New Zealand Society (Minister of Health and Associate Minister of Health, 2002). Harwood (2010) illustrates what these outcomes mean at the level of service design and service delivery in rehabilitation. Only when rehabilitation providers work with Māori to create an outcomes framework and use it to guide the development of the service will the outcomes of HKO be fully realised. In service delivery, rehabilitation providers need to work with Māori clients and their whānau to set goals that are self-determined and encompass health in its broader sense.

Wiley (2009) describes a “dual identity” (p.1206) that of being Indigenous and disabled. It therefore follows that being Māori with aphasia will have a twofold impact on language and communication behaviours. In seeking to address the requirements of the strategy documents outlined above and informed by Māori health models and knowledge of communication in Māori culture, we need to question how speech language therapy services are responding to this dual identity.

A review of the literature
We set out to review the literature to investigate whether Māori with aphasia and their whānau are being included in research, and what, if any, specific outcomes or concerns have been reported.

We searched “Māori” AND “aphasia” and “Māori” AND “dysphasia” as “anywhere in text” and as a keyword in online databases PsycINFO, ScienceDirect, PubMed, MEDLINE, CINAHL Plus, and Google Scholar. No limits were placed on publication dates. “Aphasia” and “dysphasia” are largely used interchangeably. While technically less correct, “aphasia” is the preferred term in order to prevent phonological confusion between the words “dysphasia” and “dysphagia” (the medical term for swallowing dysfunction).
PsycINFO, PubMed, MEDLINE, and CINAHL Plus returned no hits for either search.

ScienceDirect returned no hits for “Māori” AND “dysphasia”, but returned 22 hits for “Māori” AND “aphasia”, three of which were identified as possibly relevant.

Google Scholar returned 303 hits for “Māori” AND “aphasia”, 24 of which were identified as possibly relevant. Three of these had already been classified from the Science Direct result.

Google Scholar returned 158 hits for “Māori” AND “dysphasia”. Six were identified as possibly relevant, four of which had already been classified under Google Scholar “Māori” AND “aphasia”.

The following five categories were established in order to classify the extent of participation in research for Māori with aphasia. The articles were read and assigned to a relevant category (the number of articles is shown in brackets):

i. Specifically investigates aphasia in the Māori population (0)

ii. Includes Māori participants with aphasia but culture/ethnicity not specifically addressed in observations or results (0)

iii. Includes Māori participants with stroke or a condition linked to communication disorders. Presence of aphasia not stated. Culture/ethnicity specifically addressed in observations or results (4)

iv. Includes Māori participants with stroke or a condition linked to communication disorders. Presence of aphasia not stated. Culture/ethnicity not specifically addressed in observations or results (9)

v. Not relevant to this review (13)

It is particularly salient to note that no articles addressed aphasia in the Māori population or involved Māori participants stated to have aphasia (categories i and ii).

In category iii, four articles included Māori participants with stroke or a condition linked to communication disorders, presence of aphasia not stated and culture or ethnicity specifically addressed in observations or results.
Ackerley, Gordon, Elston, Crawford, and McPherson (2009) utilised a quality of life scale (the WHOQOL-BREF) and a participation scale (London Handicap Scale) to compare how the scales measure change during rehabilitation. Of the participants who completed the study, 9.1% were Māori. Ackerley et al. found improvement in most areas of quality of life and participation with no significant effect of ethnicity. Interestingly, people with severe aphasia were excluded.

Feigin et al. (2007) studied predictors of outcomes for 836 patients with “first-ever-in-a-lifetime ischaemic stroke”. They found that being Māori was one of the independent predictors of requiring assistance for activities of daily living at six months post-stroke. Being Māori and having aphasia were both independent predictors of “poor outcome” (dependency or death at six months post-stroke).

Glozier et al. (2008) studied post-stroke return to paid work in younger adults. Twelve percent of their sample was Māori. They state that the small number of Māori participants limited their options for analysis, but on univariate analysis NZ European ethnicity (among other things) was “independently associated with a higher likelihood of return to paid work at 6 months” (p.1529). While aware that the presence of aphasia may influence return to work, Glozier et al. were unable to comment on its relevance in this study. Larkins et al.(2004) consulted five stakeholder groups (including Māori), in order to identify a core list of communication activities following traumatic brain injury. The Māori group viewed some communication activities as significantly more important than the other participants. Larkins et al. concluded that more insight is needed to understand how culture, particularly Māori culture, impacts on everyday communication activities.

These four studies comment on outcomes or priorities for Māori with stroke and/or communication disorders. However, there are insufficient studies to draw any robust conclusions, the participants in the studies did not all have communication disorders, and people with aphasia were actively excluded in some.

In category iv, nine articles included Māori participants with stroke or a condition linked to communication disorders, presence of aphasia not stated and culture or ethnicity not specifically addressed in observations or results. This shows that Māori with stroke and/or communication disorders are being included in research but more often than not the research is not addressing their uniqueness. In these nine studies the number of Māori participants was often too small to allow results for Māori to be analysed as a separate group.
The above studies (categories iii and iv) showed no evidence that the research was conducted by Māori or that Māori participated in the design of the research or benefitted from the findings. The importance of this has been reported by Smith (1999) and Harwood (2010). The concept of research being done by, with, and for the population of interest has been recognised in KMR for some time (L. T. Smith, 1999). A similar concept, known as “user involvement” is just emerging in the United Kingdom (Fudge, Wolfe, & McKeivitt, 2008; Staniszewska, 2009).

**Discussion**

This review of the literature shows that Māori are over-represented in the stroke population but under-represented in the communication disorders literature. Possible explanations for this include methodological challenges and lack of recognition of the need for research in this field. It is also worth considering reasons for the anecdotal underrepresentation of Māori in speech language therapy clinics. These include the lack of community awareness of aphasia, the role of the clinician, the appropriateness of services, and the nature of aphasia.

**Methodological challenges**

The challenges of involving people with aphasia in research include such things as the need for modified assessment and therapy materials and adaptations to standard qualitative methodologies. As a result, people with aphasia have often been excluded (Hilari, Wiggins, Roy, Byng, & Smith, 2003). When research is undertaken with Māori, “Māori themselves should be involved in the design, delivery, management and monitoring of the research process” (Jahnke & Taiapa, 2003, p. 50). Although non-Māori researchers can undertake culturally sensitive research with Māori, it requires a different approach, such as bicultural research where Māori and non-Māori researchers work on a project together (L. T. Smith, 1999). This means that research involving Māori with aphasia requires the input of Māori researchers with SLT knowledge. There is a definite lack of Māori speech language therapists – Māori make up 15% of the population but less than 2% of all therapists are Māori (Harwood, 2010). It is likely that this has led to the current lack of ‘champions’ with both aphasia and KMR knowledge and experience. Given these methodological challenges, research involving Māori who also have aphasia (that is, Wiley’s (2009) dual identity) requires a unique approach.
Lack of recognition of the need for research in this field
Although NPR (Health Research Council of New Zealand, 2010) recognises the need “to build an evidence base which contributes to improved Māori health outcomes”, the absence of literature about aphasia in Māori suggests that New Zealand researchers and service providers have not yet recognised the need to address Māori perspectives on communication disorders and responses to intervention.

Lack of community awareness of aphasia
This may be a contributing factor in the underrepresentation of Māori receiving speech language therapy. Simmons-Mackie, Code, Armstrong, Stiegler and Elman (2002) carried out an international study of public awareness of aphasia. They found that while approximately 15% of people had heard about aphasia, only 5.4% of people had basic knowledge of it.

The role of the clinician and appropriateness of services
Curtis et al. (2010) discuss the roles of society, policy, and the clinician as three key factors in reducing inequalities between Māori and non-Māori in ischaemic heart disease. Although their study focuses on health promotion, this could be extended to broader health inequalities, including speech language therapy services. With so few Māori speech language therapists, the role of the clinician is likely to be making an impact on Māori involvement in aphasia therapy. Smedley, Stith, and Nelson (2003) discuss the prejudice and stereotyping that can occur when clinician and patient do not share the same cultural background. Clinicians can be well-meaning and totally unaware of their prejudice. Māori with disabilities and their caregivers have identified that their cultural needs are not being met and they do not feel they can participate as Māori in the disability sector (Wiley, 2009). This begs the question whether speech language therapy interventions for aphasia are always culturally appropriate.

The nature of aphasia
Due to the nature of their communication disorder, people with aphasia struggle to advocate for themselves. In a climate where Indigenous people need to be proactive in order to receive services (Wiley, 2009), it would appear that people with aphasia are doubly disadvantaged. That is, without “a voice with which to express their concerns” (Wiley, 2009, p. 1206) they are unable to find their way through the public health system and advocate for themselves to receive therapy. Consequently, Māori with aphasia may be under-represented in the speech language therapy clinics and the literature.
Conclusion

This literature search revealed no articles that address aphasia in the Māori population or involve Māori participants stated to have aphasia. Due to their language deficit, people with aphasia are often excluded from research. Added to this, Wiley (2009) reports the need for Māori to be proactive in order to receive services. NZDS, NPR and HKO all show a commitment to improving health and disability outcomes for Māori. However, this commitment is not reflected in the aphasia literature, and we need to question why. We have considered possible explanations for the under-representation of Māori with aphasia in the literature. Could it be due to methodological challenges and/or lack of recognition of the need for research in this field? What is the impact of the lack of community awareness of aphasia, the role of the clinician, the appropriateness of services, and the nature of aphasia? The only way to answer these questions is to ask the people concerned. Efforts to investigate aphasia in Māori require an approach that involves Māori with aphasia and their whānau, in a way that is culturally appropriate and enables them to have a voice.

References


Chapter 3: The use of interpretive description within Kaupapa Māori research


This publication is inserted as submitted for publication, with the exception of minor edits and formatting changes to maintain consistency throughout the thesis.
Abstract

KMR is an Indigenous research approach that is decolonising and transformative. ID is a qualitative methodology used to generate knowledge relevant to the applied health disciplines. In this article we discuss how we combined KMR and ID to investigate the experiences of Māori with aphasia and their whānau. This is novel because it is the first time these two approaches have been combined. In the context of aphasia research, we discuss how they are compatible in theory and how they were compatible in practice. Tensions arise at the interface between KMR and ID, particularly regarding different cultural approaches to confidentiality and knowledge-sharing. Despite these tensions, we conclude that the combination of KMR and ID enables clinicians and Māori with aphasia to learn from each other and work together to generate knowledge that makes a difference for Māori with aphasia and their whānau.
Māori health research must be culturally appropriate and benefit both Māori whānau and clinicians. In the discipline of SLT, there is no single methodology to guide such research with Māori with communication disorders. In this article we examine a possible solution to this problem - the use of the qualitative methodology ID within a KMR framework. We discuss how we combined these two methodological approaches in a study about the experiences of Māori with aphasia and their whānau. ID has been used in aphasia research (Bright, Kayes, McCann, & McPherson, 2012), and has the potential to be used with increasing frequency in this field. KMR has not previously been used in aphasia research. Indeed, there is no published literature about Māori with aphasia (McLellan et al., 2011). It is not uncommon to incorporate a qualitative methodology within a KMR study (e.g. Jones, Ingham, Davies, & Cram, 2010; Taitimu, 2007), but to our knowledge, this is the first time that KMR and ID have been brought together.

We begin with a brief introduction to qualitative research in aphasia. Following this, we outline KMR and ID individually. We then detail the background of the study and explain the decision to incorporate ID into a KMR project. This is followed by a discussion about how KMR and ID guided the study formation, data collection, and analysis. We conclude by discussing the ways in which KMR and ID are compatible and the tensions that arise at the interface between them. Although this article is about the interaction between KMR and ID, it is unique to the context of aphasia because of the necessary methodological adaptations that are required when interviewing people with aphasia. Adaptations include the need to ask more direct questions, seek clarification of words and gestures, deduce meaning from participant responses, and support the participant to explain his or her answers (Luck & Rose, 2007).

**Qualitative research in aphasia**

There is a growing body of qualitative research with people with aphasia and their family members, using a variety of qualitative methodologies and methods (e.g. Armstrong et al., 2012; Brown, Worrall, Davidson, & Howe, 2010; Davidson, Worrall, & Hickson, 2006; Howe et al., 2012; Legg & Penn, 2013). Despite this, there remains very little research involving Indigenous peoples with aphasia and we are not aware of any aphasia research employing Indigenous methodologies. The most comprehensive study published so far exploring the experiences of Indigenous peoples with aphasia is that of Armstrong, Hersh, Hayward, Fraser and Brown (2012). This was a cross-cultural pilot project involving semi-structured interviews with Aboriginal people with aphasia in Western Australia. Armstrong
et al. did not detail their qualitative methodology but they discussed the methods at length. In a similar cross-cultural study Legg (2010) used an ethnographic approach to investigate the social and cultural implications of stroke and aphasia in Khayelitsha, a South African township. Although it was not focused on a particular Indigenous group, Legg’s research had a cultural (as opposed to linguistic) focus similar to that of the current article. She provided insight into the effect that culture has on experiences of aphasia and commented on methodologies appropriate for use in that setting.

Kaupapa Māori research

Kaupapa Māori is not usually described as a methodology per se. It has been called a research approach that “provides a methodology or philosophy that guides Māori researchers” (Cram, 2001, p. 41) and “more than a methodology and less than a methodology… something much more fluid” (L. T. Smith, 2011, p. 10). As a research approach, KMR is well-recognised and valid (Bishop, 2005; Cram, 2001; Irwin, 1994; Pihama, 2011; L. T. Smith, 2005, 2011, 2012; Walker, Eketone, & Gibbs, 2006). It has underpinned research in education (Irwin, 1994; Pihama, 1993; G. H. Smith, 1997), clinical psychology (Taitimu, 2007) and health (Elder, 2008; Harwood, 2012; Kerr, Penney, Moewaka Barnes, & McCleanor, 2010; Pitama et al., 2011). This section contains an overview of the theory and principles of KMR, followed by an outline of the guidelines for KMR processes.

Pihama (1993, p. 39) described Kaupapa Māori theory as a “theoretical position” within the critical theory framework. Therefore, an important aspect of KMR is the analysis of power:

Intrinsic to Kaupapa Māori theory is an analysis of existing power structures and societal inequalities. Kaupapa Māori theory therefore aligns with critical theory in the act of exposing underlying assumptions that serve to conceal the power relations that exist within society and the ways in which dominant groups construct concepts of “common sense” and “facts” to provide ad hoc justification for the maintenance of inequalities and the continued oppression of Māori people (Pihama, 1993, p. 56)

KMR strives for Māori self-determination and empowerment; the control of the research is in Māori hands (Bishop, 2005; Walker et al., 2006). As decolonising research (Pihama, 2011), KMR privileges Māori knowledge and ways of knowing (L. T. Smith, 2012). It challenges dominant constructions of research (Walker et al., 2006) and challenges Māori researchers to question their own beliefs that have come from colonial attitudes (Pihama, 2011; L. T. Smith, 2012). The decolonising aspects of KMR are best illustrated with the
following extract from the research journal of the first author. In this passage I reflect on a presentation I delivered to a group of academics and postgraduate students and how the experience enabled me to better understand dominant constructions of research and my own colonised beliefs:

After my presentation, an academic asked me if this type of study has been done in “other people”. I asked her to clarify “other people” and she floundered a bit before saying “other cultural groups”. I wasn’t prepared for this sort of question so didn’t respond very well. I told her that we don’t have such information for any group of people and this limits our ability to compare the findings to other research. She recommended I include another (implied: Pākehā) group for comparison and I said no, but if another student wanted to do it that would be good. I didn’t fully understand the implications of this question until a fellow Māori student was asked the same question about her research and she responded beautifully.

While listening to the other student’s response I realised that, in asking this question, the academic was asking me to justify the research, seeing it as only valid if Māori were researched as “other”. This led me to a vital understanding of kaupapa Māori research. In KMR, Māori are not studied as “other”. Māori are studied by Māori because people do research with their own people. Pākehā researchers are not called to compare their findings to another cultural group, neither should Māori be. I had read this but I didn’t understand it until now. I had to feel it before I could understand it. Now when I am asked to justify my research (as will undoubtedly happen) I will explain that comparison is not necessary because this is research by Māori, for Māori, conducted in the Māori world, and in KMR there is no expectation that one go outside that world. It is important for me to demonstrate this because otherwise I am encouraging the view that Māori research is only valid in comparison to other research.

As transformative research, KMR aims to effect changes that will benefit Māori; “we don’t theorise for theory’s sake” (Pihama, 2011, p. 51). Research involving Māori is not always beneficial for Māori and not always about what Māori want to know (Pihama, 2011; L. T. Smith, 2012). The idea that health research might not be of value to Māori might be challenging for health researchers. It is likely that anyone undertaking research about Māori health has benevolent intentions, but it is incorrect to assume that research will be beneficial (L. T. Smith, 2012). Decisions about the validity of the research are intertwined with the validity of the researcher (Walsh-Tapiata, 2003). The researcher’s personal qualities, identity and family connections are very important. Similarly, relationships between researchers and people involved in the research are fundamentally important, both during design and throughout the study. The relationships are reciprocal (L. T. Smith, 2005) and endure beyond the length of the project (Cram, 2001; Pihama, 2011). The researcher is
personally involved in the research process, not as an individual but as a member of the research whānau (Bishop, 2005). This means being involved “physically, ethically, morally, and spiritually, not just in one’s capacity as a ‘researcher’ concerned with methodology” (Bishop, 2005, p. 130).

There is ongoing discussion about whether one must be Māori to undertake KMR (Bishop, 2005; Cram, 1997, 2001; Jahnke & Taiapa, 2003; Walsh-Tapiata, 2003). While it is recognised that being Māori is not a guarantee of appropriate researcher conduct (Bishop, 2005), and that non-Māori can support Māori research (Bishop, 1996; Cram, 1997, 2001; Walsh-Tapiata, 2003), KMR requires “actual Māori experience” (Jahnke & Taiapa, 2003, p. 50). Discussing non-Māori involvement in KMR, Bishop (2005, p. 113) summed up KMR as “Māori research by Māori, for Māori with the help of invited others”. Reflecting on the process of conducting KMR within her own iwi, (Walsh-Tapiata, 2003) explained that when KMR is undertaken by Māori it is likely to produce a higher quality result. “The appropriate genealogical connections (whakapapa) and my commitment to the iwi facilitated my access to a wealth of research information and to understanding that would not be accessible to mainstream researchers” (p. 58).

KMR is often undertaken in partnership with an iwi or a Māori community and overseen by the elders of that community (Rāwiri, 2011; Walsh-Tapiata, 2003). These partnerships are guided by KMR principles which in turn guide KMR processes. True partnerships can only be formed when iwi are respected as self-determining (Rāwiri, 2011). When research is undertaken by a researcher with connections to the iwi or community, the focus is on the researcher’s accountability to their whānau, hapū, and iwi and on building up their knowledge and skill base and therefore the iwi’s capacity (Walsh-Tapiata, 2003). Te reo Māori is very important in KMR (Rangahau, 2013). However, language loss through colonisation has created an environment in which this can be difficult. In principle KMR aims to revitalise te reo Māori, although the research process is often undertaken in a mix of te reo and English because many Māori researchers and participants are not fluent in te reo (Walker et al., 2006).

Fiona Cram and Linda Smith have outlined seven “guidelines about Māori research ethics” (Cram, 2001). These are guidelines for KMR process, as opposed to the theory and principles discussed above (Cram, 2001; L. T. Smith, 2012). They form basic kaupapa Māori practice and give ethical guidance over and above any requirements placed by an
ethics committee. We will briefly explain the guidelines here and discuss how they were applied later in the article.

- “Aroha ki te tangata (a respect for people)” (L. T. Smith, 2012, p. 124). A kaupapa Māori researcher applying this guideline will allow participants to “define their own space and meet on their own terms” (Cram, 2001, p. 42).

- “Kanohi kitea (the seen face, that is present yourself to people face to face)” (L. T. Smith, 2012, p. 124). Kanohi kitea is about “fronting up” to the people who will participate in the research and demonstrating that “the researchers are willing to cross that space between researchers and researched” (Cram, 2001, p. 43).

- “Titiro, whakarongo . . . kōrero (look, listen . . . speak)” (L. T. Smith, 2012, p. 124) is applied to many situations in the research process. It emphasises the importance of learning through looking and listening before beginning to speak (Cram, 2001).

- “Manaaki ki te tangata (share and host people, be generous)” (L. T. Smith, 2012, p. 124) involves a joint approach to research in which the researcher does not just conduct research but learns from the participant. This collaboration extends to sharing the findings of the research with the participants (L. T. Smith, 2005), motivated by a spirit of reciprocity rather than knowledge transfer and exchange.


- “Kaua e takahia te mana o te tangata (do not trample over the mana of people)” (L. T. Smith, 2012, p. 124). Mana is a complex and important Māori concept. It is sometimes translated as prestige or dignity. This guideline is about being respectful throughout the research process, engaging with the community and sharing research findings (Cram, 2001).

- “Kia mahaki (don’t flaunt your knowledge)” (L. T. Smith, 2012, p. 124). This final guideline follows naturally from the others. If a researcher is respecting others, listening, being cautious, and not trampling on people’s mana, they will most likely also be humble when sharing their knowledge.
**Interpretive description**

ID is a qualitative methodology that originated in nursing. Its roots are in the three traditional qualitative methodologies – ethnography from anthropology, grounded theory from sociology, and phenomenology from philosophy. Morse (1989) questioned whether these methodologies are research tools that can be applied across disciplines, or whether each is inherently linked to the existing doctrine of its discipline. Over time health researchers found that the theoretical nature of the traditional methodologies did not meet the needs of their applied health disciplines. Morse (1989) identified that qualitative methodologies were becoming increasingly diverse as researchers in nursing adapted traditional methodologies to suit their specific needs. She called the result “a sloppy mishmash” (p.15) but also acknowledged that some qualitative researchers do “legitimate qualitative research for which, as yet, there is no name” (Morse, 1989, p. 18). In 1997 Thorne and colleagues named ID, thereby providing a name for the high quality, yet nameless, methodology that was already being used in nursing research (Thorne, 2008; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). Thorne later referred to ID as “a disciplinary approach to qualitative research” (2008, p. 73).

ID is an applied methodology and is “somewhat atheoretical” (Thorne, 2008, p. 70). It aims to create clinically relevant and clinically applicable findings. ID is inductive. The researcher does not set out with an existing theory and look for data that prove or disprove it. Rather, one looks at the data and develops codes from that and the codes change, develop, and grow as the analysis proceeds. ID is firmly situated within a discipline. ID researchers recognise the existing knowledge that the discipline holds, and how that will influence the research. They do not set aside or bracket disciplinary knowledge and personal experiences but attempt to minimise the unintended impact the individual researcher has on the research (Thorne, 2008).

Thorne (2008, pp. 74-75) outlined the “foundational underpinnings” which “represent the epistemological foundation of interpretive description”. She acknowledged that many of them are informed by naturalistic inquiry (Lincoln & Guba, 1985), which is now known as constructivism (Guba & Lincoln, 1994). The foundational underpinnings are listed below. We will demonstrate how we applied them in the current study later in the article.

- ID is used to illustrate commonalities and individual differences within the area of interest
• ID researchers:
  o value the clinical insight gained from subjective and experiential knowledge
  o pay attention to the context in which the research takes place, although the issues being researched are not unique to one context
  o acknowledge the inseparability between knower and known and the way that the researcher and the participant influence each other
  o acknowledge that human experience is socially constructed and can involve many contradictory realities
  o are attentive to the participants’ ethical rights and comfort and undertake research in the most naturalistic setting possible

Background to the study

In this section we introduce the project in which we incorporated KMR and ID. By presenting the background of this study we provide the context for later discussion about the strengths and challenges of applying KMR and ID. The findings of this study are presented in Chapters 4 and 5. This study investigated the experiences of Māori with aphasia and their whānau. Aphasia is an acquired language disorder that affects one’s ability to understand spoken language, speak, read, write, and use numbers. As many as 25-30% of people who have a stroke will acquire aphasia (Dickey et al., 2010; Engelter et al., 2006; Kauhanen et al., 2000).

The World Health Organization (2001b, p. 12) states that health services should be culturally appropriate, that is “respectful of the culture of individuals, minorities and indigenous populations”. This is fundamental to health care provision. When the World Health Organization’s requirements are considered alongside the NZDS (Minister for Disability Issues, 2001) and HKO (Minister of Health and Associate Minister of Health, 2002), it is clear that all clinicians in NZ need to consider the most appropriate way to provide services for Māori. For SLTs, Māori with aphasia and their whānau are a small but significant group. However, given that there is currently no research about the experiences of Māori with aphasia (McLellan et al., 2011), SLTs do not have access to the knowledge or resources necessary to provide an appropriate service.

In light of this, the current study aimed to a) describe the experiences of Māori with aphasia and their whānau and b) determine ways in which SLTs might learn from these experiences.
to be better equipped to provide services for Māori clients. We envisaged that the findings would be used to help Māori with aphasia and their whānau make sense of their experiences, and to increase SLTs’ understanding of the experiences of their Māori clients with aphasia. Data were gathered via in-depth semi-structured interviews with 11 Māori with aphasia and their nominated whānau members. The participants, from diverse backgrounds, came from iwi throughout the North Island of New Zealand. Interviews probed the whānau’s experience of stroke and changes that had taken place since the stroke, with a particular focus on communication. Specific areas included relationships, activities, spirituality, health and roles in the family and community.

**Reasons for combining KMR and ID**

The project was KMR right from its inception, because this is the most appropriate way to undertake research addressing a Māori issue with Māori participants. As discussed above, an essential principle of KMR is that the research benefits Māori. Therefore, the findings of this study needed to be relevant to, and accessible for, Māori with aphasia and their whānau as well as SLTs. Although this was a kaupapa Māori project and control was in Māori hands, we recognised the reality of the New Zealand SLT workforce and service provision. All SLTs are trained in mainstream universities and very few SLTs are Māori. In addition, there are very few Māori service-providers that offer SLT services. Therefore, to make the research applicable to, and understood by, non-Māori SLTs as well as Māori with aphasia, we decided to incorporate a qualitative methodology with the KMR framework. We considered several different methodologies and investigated whether they would be compatible with KMR.

**Qualitative description**

Qualitative description aims to provide an unembellished description of an event or experience (Sandelowski, 2000) and has been used successfully in aphasia research (Howe, Worrall, & Hickson, 2008). We ruled out qualitative description for this study, deciding that the critical aspects of KMR were better suited to an interpretive methodology.

**Ethnography**

Ethnography studies the behaviours and perspectives of a group of people (Richards & Morse, 2007). Ethnography has been used successfully with people with aphasia (Legg, 2010). We decided against using ethnography for this project for two reasons. We aimed to focus not on the behaviours of Māori with aphasia and their whānau, but solely on how they
perceive their experiences. In addition, ethnographic studies are usually undertaken by people who are not part of the cultural group being studied (Richards & Morse, 2007) while KMR requires the researcher to be Māori.

**Participatory action research**

In participatory action research the participants determine the research topic, questions, methods of data collection and analysis, write-up and dissemination of findings (Richards & Morse, 2007). As well as being participant-led, participatory action research has a focus on social justice and empowerment of marginalised peoples (Eruera, 2010). This approach fits well with KMR (Eruera, 2010) and would have been appropriate for this study. However, there are a relatively small number of people with aphasia in New Zealand and any one iwi, hapū or Māori community is unlikely to have more than a few people with aphasia. Therefore, undertaking this project within a particular community or group was not feasible. To undertake participatory action research we would have had to create a community of Māori with aphasia and whānau members and this very act would have made the study researcher-led rather than participant led.

**Phenomenology**

Phenomenology in communication disorders research focuses on how individuals understand and interpret their experiences (Meline, 2006). It can be used successfully in aphasia research (Luck & Rose, 2007). However, phenomenology requires that the researcher “bracket” their existing knowledge and beliefs about the topic (Willig, 2001). This is not appropriate for the KMR researcher who is involved in the research “physically, ethically, morally, and spiritually” (Bishop, 2005, p. 130).

**Interpretative phenomenological analysis**

We initially chose interpretative phenomenological analysis as the most suitable methodology for this study. It has been used with people with aphasia (Brown et al., 2010) and has been successfully combined with KMR (Borell, 2005; Elder, 2008; Jones, Ingham, Cram, Dean, & Davies, 2013). Being phenomenological, this methodology has a focus on the way people understand and perceive their experiences, which would be appropriate for the focus of this study. The interpretative aspects of interpretative phenomenological analysis recognise that the researcher is “necessarily implicated in the analysis” (Willig, 2001, p. 67), which is compatible with KMR. Interpretative phenomenological analysis would have been a suitable methodology for this study, but we deemed ID to be more appropriate because of its emphasis on clinically applicable research within a discipline.
Interpretive description
We chose ID as an appropriate methodology to combine with KMR for several reasons. It has been used successfully in research about hope in people with aphasia (Bright et al., 2012). With its focus on applied research that creates clinically-relevant findings, ID is compatible with KMR’s aim of being transformative. That is, both aim to make a positive difference in people’s lives. Both are non-prescriptive when it comes to methods of data collection and analysis, which means that when combined, each allows the other the flexibility to proceed. Both acknowledge who the researcher is and the existing knowledge that s/he brings to the research (Bishop, 1996; Thorne, 2008). And, both recognise that knowledge is jointly constructed between researcher and participant rather than being already in existence and waiting to be discovered (L. T. Smith, 2011; Thorne, 2008).

Having described the principles behind KMR and ID, and why we chose to combine them in this project, we now turn to their practical application and the research process. We discuss the joint contribution of KMR and ID to the formation of the study, participant, data collection, and data analysis.

How KMR and ID guided the research process
Because there is no published research using both KMR and ID, there were no precedents for combing the two. Our background reading suggested that KMR and ID would be compatible in many ways but that there would be areas of tension, as is inevitable when bringing together two paradigms. In practice we discovered that KMR and ID worked well together most of the time, sometimes almost synergistically. Differences became most evident in the detail that each research approach either emphasised or did not mention. The differences were often expressed more strongly by what was not mentioned. This is because that which is not mentioned is taken for granted and this in itself is an epistemological and ontological statement. Because KMR and ID emphasise different aspects of the research process, in some parts of this research KMR was more prominent and in others ID was more prominent.

Validity of the research topic and researcher
Both KMR and ID contributed to the formation and validation of the research topic. KMR is transformative and decolonising. Therefore the research must benefit Māori and it is Māori who must determine this. ID aims to create clinically relevant and clinically applicable findings. That is, findings of benefit to clinicians. Therefore, a study about aphasia which
combines KMR and ID must be validated by Māori with a connection to aphasia and by SLTs.

Impetus for this study came from a Māori SLT working in a stroke unit, and from Māori with stroke who identified that they needed more input from SLTs (Harwood, 2012). During the project’s development we formed a rangahau whānau (Irwin, 1994). This group was led by a kuia whose sister had aphasia. The rangahau whānau confirmed the validity of the research topic and the researcher. Throughout the research we continued to receive approval from the rangahau whānau, participants, SLTs, and in clinical and Indigenous forums.

**Naming participants**

The first few participants made suggestions as to how to improve the process. The first family to be interviewed asked that they be named on reports arising from the research, and that their real names be used when they were quoted. When participants are named it enables the reader to see where the data have come from and therefore can add validity to the research (Walsh-Tapiata, 2003). The ethics committee approved this approach, in consultation with the rangahau whānau. Following that, we offered all participants the opportunity to be named and most accepted it. This dialogue between participants, researcher, and rangahau whānau is an example of the KMR ethical principle of aroha ki te tangata (a respect for people). As such, it is “respectful of the . . . ethical rights of all participants” (Thorne, 2008, p. 74) as required by ID. Naming participants goes against the confidentiality that is usually required in ID. However, as the two research approaches worked together in this situation, KMR guided the interpretation and practical expression of ID’s ethical requirements.

**Informed consent**

Informed consent is an important component of research, KMR and ID included. Both research approaches provided guidance on this process. As well as ID’s moral and ethical requirements, we were guided by two KMR principles - kaua e takahia te mana o te tangata (do not trample over the mana of people) and kanohi kitea (meet people face to face).

When participants have difficulty communicating one must be particularly careful not to trample on their mana, and meeting face to face is an important element of that. Kagan (1998, p. 820) promotes “acknowledgement of competence” and “revealing competence” of people with aphasia. Acknowledgement of competence can be implicit, e.g. using an appropriate adult tone of voice in conversation, or explicit, e.g. openly acknowledging that
the person with aphasia knows what they want to say even though they cannot find the words. Competence is revealed through enabling the person with aphasia to communicate, ensuring that they understand and asking questions in a way that they can answer. Acknowledging the competence of a participant with aphasia includes acknowledging their ability to give informed consent. Revealing their competence involves presenting the information in a way that genuinely informs them. Actions that acknowledge and reveal the competence of someone with aphasia begin to acknowledge and reveal their mana. However, mana cannot be reduced to competence and neither ID nor current aphasia communication strategies provide sufficient guidance for how to uphold it.

As the study progressed it became clear that it was important to schedule an initial face-to-face meeting with potential participants to establish a relationship that would uphold their mana. On that first visit we had no expectation of completing an interview, or even gaining informed consent. The visit focused on whakawhanaungatanga (a process of establishing relationships), discussing the project and ascertaining how to help the person with aphasia to communicate. This initial meeting did not happen with all participants. When it did take place it was noticeable that things went more smoothly during the subsequent interview.

ID provided guidance about the need to confirm on-going informed consent. During an interview participants can reveal deeply personal or emotional information and the interviewer must try to ensure that participants do not reveal more than they are comfortable with. The interviewer continually obtains informed consent by noticing when the subject matter is deeply personal and giving the participant the opportunity to stop and revise whether they wish to continue (Thorne, 2008). Participants in this study spoke about a difficult and emotional topic and relived some painful memories. When participants became emotional during the interviews we invited them to stop and take a break or to move on and speak about a different topic. In addition, we offered all participants the opportunity to check the transcripts of their interviews, which were provided in their chosen format (written or audio). We asked participants to remove any information they did not want included and we offered to visit to discuss anything they wished to discuss. This served to not trample their mana, as required by KMR, and establish the on-going informed consent required by ID.

**Interviews**

With ID, the options for data collection techniques are “infinite” (Thorne, 2008, p. 125), although participant observation, focus groups and interviews are commonly used. KMR
does not dictate data collection methods, although kaupapa Māori researchers evaluate methods as to their suitability for Māori research (Cram & Kennedy, 2010). We chose not to undertake participant observation because we were interested in the experiences of Māori with aphasia and their whānau as they perceive them, not how they appear to an observer. Although we were speaking to whānau groups, we chose to conduct group interviews rather than focus groups. This enabled flexibility for individual whānau because an interview could take place with as few or as many people as wished to be involved.

Participants with aphasia chose where the interviews took place and who to include as their whānau members. The majority of the interviews (16 out of 17) took place at the participants’ homes, with one taking place at a marae. These settings, including location and people present, were natural and comfortable for the participants. This was guided by both ID and KMR. ID researchers are attentive to the participants’ ethical rights and comfort and undertake research in the most naturalistic setting possible (Thorne, 2008). The KMR principle of aroha ki te tangata (a respect for people) entails “allowing people to define their own space and to meet on their own terms” (Cram, 2001, p. 42). Meeting on participants’ terms is deeper and more complex than providing a naturalistic setting. Meeting in the participant’s space reduces differences in power between researcher and participant (Taitimu, 2007), which is very important in KMR.

The interviewer’s approach during interviews was informed by KMR and ID. The main guiding principle was titiro, whakarongo . . . kōrero (look, listen . . . speak). Looking and listening before speaking is good practice for interacting with people with aphasia, who tend to need more time to process language and formulate their reply. It is also a valuable approach when conducting qualitative interviews because it indicates to the interviewee that they are giving valuable information and should continue (Patton, 2002). Thorne (2008, p. 110) wrote of a similar process which she called “learning not to lead”. She reminded the clinician researcher that the interview is different to a clinical consultation and s/he must step out of the role of clinician and into the role of naïve listener. Both ID and KMR recommend active and humble or naïve listening. However, there is a fundamental difference in the motivations between the two. In ID listening before speaking is motivated by “becoming an effective researcher” (Thorne, 2008, p. 110) whereas in KMR it is an ethical principle.
Data analysis

KMR and ID informed the data analysis in two ways. They guided the ontological and epistemological approach to the data, and the practical process of conducting the data analysis. In ID, the researcher acknowledges that the issues being researched are not unique to one context, but s/he recognises the context in which the research takes place. Aphasia is not bound by time or place. Consequently, neither are many of the issues raised in this study. However, we recognise that the experiences of the participants have been, and continue to be, influenced by multiple contextual factors. Contextual factors include family circumstances and the accessibility of health care and rehabilitation at the time they had the stroke and in the place where they live(d). Given this, some aspects of the findings will be applicable to other Māori with aphasia, and probably some non-Māori with aphasia. However, the findings cannot be taken as representative of anyone other than the 11 participating families.

KMR involves an analysis of power and societal inequalities (Pihama, 1993). This guided our thinking as we took a critical approach to data analysis. An example of this is when analysing the data about participants’ experiences of SLT. Most participants spoke positively about SLT, with only one family overtly describing negative experiences. On the surface it appeared that current practices in SLT might be meeting the needs of Māori with aphasia. However, KMR encouraged us to look deeper and include an analysis of power and societal inequalities. This revealed that, although they expressed satisfaction with SLT services, many families were doing a lot of the work themselves. It was whānau, not SLTs, who were enabling the person with aphasia to participate in te ao Māori.

The work done by whānau rather than SLTs is best illustrated by one of the participants, a man with nonfluent aphasia. Despite having very limited expressive language ability, this man maintained an admirable level of involvement in his community. He taught at the local kura kaupapa Māori in a voluntary capacity and maintained roles on his marae committee and at a sports club. This community involvement was facilitated by his wife and fellow community members, not by his SLT. At the time of his interview the participant had been going to weekly therapy at a hospital clinic for several years. He and his wife spoke highly of his SLT and valued the input. However, because there was no community SLT service, the SLT’s role was very limited. If the participant had been reliant on his SLT to facilitate his community involvement he would not have got very far. As much as he and his wife valued the input of his SLT, his therapy sessions were something he did once a week by
himself and were entirely separate to his community life. If this man’s story were analysed outside of a KMR framework it might have focused on the whānau’s expressions of satisfaction with the SLT service, thereby providing more “justification for the maintenance of inequalities” (Pihama, 1993, p. 56). The analysis of power that is so important in KMR does not feature in ID.

Both KMR and ID acknowledge who the researcher is and the existing knowledge that s/he brings to the research (Bishop, 1996; Thorne, 2008). In ID this is partly expressed by acknowledging the inseparability between knower and known and the way in which researcher and participant influence each other (Thorne, 2008). In KMR it is linked to the concept of the researcher being wholly involved in the research process (Bishop, 2005). ID requires that the researcher attempt to minimise any unintended impact their existing knowledge might have on the research (Thorne, 2008). Therefore, before we began interviewing participants we reflected on our preconceived ideas about Māori and aphasia and SLT. We then referred to this written reflection after data analysis to ensure that the findings were not preconceived. Although this action is not common in KMR, it is not incompatible with a KMR approach because it acknowledges who the researcher is and what they bring to the research.

ID does not use member checking, where the interviewer returns to individual participants to check the understanding of what they said. Instead, in ID the researcher returns to individual participants with the beginnings of analysis from all participants and gives them the opportunity to reflect on how their own experience fits with the synthesis of the group’s experience. This approach facilitates extension of the analysis because, rather than confirming that the researcher has understood what each individual said, it confirms the extent to which the overall findings reflect all of the participants’ experiences. Thus, the findings do not necessarily describe an individual’s experience but incorporate many experiences, moving to a higher level of analysis so that even the participants themselves can learn about their experiences through seeing them interpreted and described in a bigger context (Thorne, 2008). In this project we revisited all available whānau. The revisits were all positive. Participants engaged in discussion about the model that we presented and talked about what reflected their experiences and what did not.

The analysis moved to a deeper level following those visits. Revisiting participants is recommended in ID studies as a useful part of data analysis. From a KMR perspective, the
Advantages and tensions in combining KMR and ID

We chose to combine KMR and ID in a study about the experiences of Māori with aphasia and their whānau because of the potential for the two approaches to work well together. Having completed the study we can now reflect on how the two worked together in practice. In the following sections we discuss how the two proved to be compatible, or not, and the ways in which apparent tensions turned into advantages.

Advantages of combining KMR and ID

Throughout this article we have discussed ways in which KMR and ID are compatible and illustrated this with examples of how we applied them together. We will now briefly address ways in which KMR and ID were not just compatible but synergistic. That is, when using them together we could achieve more than we could by using either one alone.

ID requires the researcher to acknowledge his/her clinical knowledge but step outside the clinical role and be a learner (Thorne, 2008). In the principle kia māhaki (don’t flaunt your knowledge) KMR provides further motivation and guidance for how to be a learner. In this research we were always conscious that the participants are the experts in this field. No-one knows more about being Māori and having aphasia than they do.

The combination of KMR and ID determined how data analysis proceeded and which data were considered important. The use of KMR meant that we constantly asked ourselves ‘how is this relevant to Māori?’ The use of ID meant that we constantly asked ‘how is this useful for a clinician?’ Using the two together ensured that we considered the relevance of the research for both Māori and clinicians in a way that is important for both but could easily be overlooked if we were only using one or the other.

Tensions that arose when combining KMR and ID

The tensions that arose between KMR and ID were ways in which one approach did not allow the other to function to its fullest extent. Because they come from different paradigms, KMR and ID differ in their approach to knowledge sharing. This is best illustrated by an interaction between the first author and Raewyn, the daughter of a woman with aphasia. After checking the transcript of her interview Raewyn asked me to return to see her. She had identified an area she was not happy with. I drove some distance to see her and when I
arrived she acknowledged how humbled she felt that I had come so far. Raewyn explained that I needed some special cultural knowledge to correctly interpret her mother’s story, which she then shared with me. Raewyn labelled this knowledge “for your ears only”. She was giving it to me to help me develop as a Māori researcher and to enable me to better interpret her mother’s story, but I was not to pass it on. Restrictions on the sharing of knowledge are common in te ao Māori (Jahnke & Taiapa, 2003) but not generally in research. ID emphasises the importance of on-going informed consent, ensuring the participant only discloses that which they are comfortable to disclose (Thorne, 2008). Raewyn was comfortable disclosing this information, but only because within a kaupapa Māori framework she could restrict its use. ID does not make provision for the restriction of knowledge dissemination.

**Tensions that became advantages**

Some of the areas of tension turned out to be advantages when we approached them in a different way. Thorne (2008, p. 37) stated that “anyone can gather data and make claims… but only those who have credibly located themselves within the scholarship of a discipline and/or the mandate of a profession can legitimately generate qualitative findings that have meaning as empirical disciplinary knowledge”. With its emphasis on the researcher gaining credibility through their discipline and profession, at face value this statement is in conflict with KMR. However, kaupapa Māori researchers face an equally stringent requirement to demonstrate their legitimacy. In KMR the emphasis is on the researcher’s genealogical connections and personal qualities (Walsh-Tapiata, 2003). When KMR and ID are used in combination, the researchers need to prove their validity in both ways. This restricts who can undertake the research, but it will lead to research being conducted by both highly skilled and well-connected individuals or groups.

Both ID and KMR have very practical applications and are not about creating theory but about making a positive change (Pihama, 2011; Thorne, 2008). However, they differ greatly in who ‘controls’ the research agenda and the ways in which they evaluate the validity and potential benefits of the research. KMR emphasises that Māori control the research agenda (Bishop, 2005) but in ID there is no discussion about control of the research. One can only presume that this is because in ID it is taken for granted that the researcher controls the research.

ID is used for clinically motivated research that produces clinically relevant findings. It is initiated by clinicians motivated to address problems or gaps in the knowledge of their
discipline (Thorne, 2008). “Moral defensibility” (Thorne, 2008, p. 226) dictates that health researchers should only undertake research if it is likely to benefit the people that they serve. Thorne (2008) places great emphasis on the literature review as a means of justifying that the proposed area of research is worthy of study: “you don’t get to claim that something constitutes a researchable problem until you have done your homework to build the case that it isn’t already known and that it is, in fact, worth knowing” (p.45). In contrast, comments about reviewing the literature barely feature in writings about KMR. “The notion that empirical evidence is sounder than cultural knowledge permeates western thought but alienates many Indigenous scholars” (Wilson, 2008, p. 58). Moreover, Wilson (2008, p. 43) explained that for Indigenous scholars a critical review of the literature would not be appropriate because “criticizing or judging would imply that I know more about someone else’s work and the relationships that went into it than they do themselves”. In KMR, confirmation that the proposed research is valid is not achieved through reviewing the literature. Irwin (1994) outlined the process she went through to gain approval from her university, her supervisors, the community, potential participants and their whānau. She concluded that the research was valid when “In every community we visited the response was supportive: this research is timely, you should do it” (p.34). This tension could become an advantage when Māori and clinicians work together. Because both groups are involved in the delivery of services and both have different needs, if they work together synergistically both can benefit in a way that could not be achieved independently.

Conclusion

KMR and ID come from different paradigms and different world views. As such, each emphasises different aspects of research theory and process. As a critical approach to research, in KMR the emphasis is on decolonising and transformative research involving an analysis of power. Relationships are vitally important and ways of relating to people are addressed in the ethical guidelines for the research process. ID research is clinically motivated and sits firmly within a discipline. Therefore, the focus is on creating relevant and clinically applicable findings while recognising the existing knowledge within the discipline. Despite their differences, both research approaches aim to produce relevant findings that will make a difference in people’s lives. This common aim means that the two can be successfully integrated in aphasia research, as has been demonstrated for the first time in this study. When KMR and ID are brought together in clinical research with Māori with aphasia, each fills gaps left by the other. KMR ensures that Māori are in control of the
research and it is conducted in a way that is decolonising. ID acknowledges the role of the
discipline of SLT and the reality that most SLTs are non-Māori and most SLT services are
provided in the mainstream. Together KMR and ID enable SLTs and Māori with aphasia to
learn from each other and move forward together to generate knowledge that makes a
difference for Māori with aphasia and their whānau members.

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Chapter 4: “For Māori, language is precious, and without it we are a bit lost”: Experiences of Māori with aphasia and their whānau


This publication is inserted as submitted for publication, with the exception of minor edits and formatting changes to maintain consistency throughout the thesis.
Abstract

**Background:** Experiences of aphasia are shaped by culture. Therefore, to provide appropriate services for people with aphasia, SLTs must understand aphasia from their cultural perspective.

**Aims:** This study aimed to describe and interpret the experiences of Māori with aphasia and their whānau, to inform service delivery for this population.

**Methods & Procedures:** This study is kaupapa Māori research, an Indigenous research approach that privileges Māori culture and knowledge. A qualitative methodology, interpretive description, was incorporated to produce clinically-relevant findings that will benefit SLTs and Māori.

In-depth interviews were undertaken with 11 Māori with aphasia and their nominated whānau members. Participants spoke about aphasia-related changes in relationships, health, spirituality, activities, and family and community roles. Analysis was informed by interpretive description and kaupapa Māori.

**Outcomes & Results:** Participants described a range of positive and negative experiences of aphasia. These developed into two pairs of themes – 1) “Grieving for what is lost” and “Recognising what we’ve got” and 2) “It’s hard” and “Choosing how to respond”.

**Conclusions:** Aphasia can have a profound effect on Māori families and bring many changes in family roles and relationships. Despite difficulties, whānau can actively manage their situation, and enable the person with aphasia to participate in the whānau and community. The findings of this study will inform clinical practice and provide the basis for the development of resources for use in SLT services for Māori with aphasia and their whānau.
This paper presents the findings of a qualitative study about the experiences of Māori with aphasia and their whānau. Māori are the indigenous peoples of New Zealand. The title, which is a quote from the daughter of a Māori woman with aphasia, illustrates how the loss of language can be of considerable importance for Māori.

There is very little research about aphasia and Indigenous peoples. A pilot study by Armstrong et al. (2012) explored the experiences of aphasia for three Aboriginal men in Western Australia. The participants demonstrated that they valued independence and wanted to control their own recovery. They spoke minimally about their aphasia, instead focusing on other aspects of their identities. The authors described the situation as “an implicit valuing of communication, but no accompanying story of obvious barriers identified as relating to the aphasia” (p. 278). They noted that the stories of Aboriginal people with aphasia are often not heard and they emphasised the need for more research in this area.

Experiences of aphasia are known to be shaped by culture. Legg (2010) demonstrated this in an ethnographic study of the experiences of adults with aphasia in Khayelitsha, a poor township on the outskirts of Cape Town. She concluded that participants’ responses to aphasia “were shaped by cultural practices and the world views through which they interpreted their lives” (p. 240). There is currently no published research focusing on the implications of aphasia for Māori (McLellan et al., 2011), but there is evidence to suggest that it is an area worthy of attention. Exact numbers of Māori with aphasia are not known. However, Māori aged over 35 years are hospitalised with stroke twice as often as non-Māori (Ministry of Health, 2010), and approximately one third of people who suffer a stroke will acquire aphasia (Dickey et al., 2010; Engelter et al., 2006; Kauhanen et al., 2000). This suggests that the incidence of aphasia for Māori will be higher than that for non-Māori. In her study of stroke recovery for Māori and their whānau, Harwood (2012) identified the need for more SLT and guidance for people with stroke and their families. It is not clear whether Harwood’s participants were referring to aphasia or dysarthria, but it is likely to be a combination of the two.

Aphasia is known to effect changes in family roles and negatively impact family relationships (Grawburg et al., 2013a; Grawburg, Howe, Worrall, & Scarinci, 2013b; Hallé, Duhamel, & Le Dorze, 2011; Le Dorze & Brassard, 1995; Michallet et al., 2003) and intimate relationships (Grawburg et al., 2013a; Le Dorze & Brassard, 1995; Lemieux, Cohen-Schneider, & Holzapfel, 2001). Māori health models Te Whare Tapa Whā (Durie, 1998) and Te Wheke (Pere, 1984) both recognise that family relationships are an integral
part of Māori health. In her writing *Extensions on Te Wheke*, Love (2004, p. 43) pointed out that for Māori “the health and well-being of the individual and the whānau are indivisible”. Therefore, if whānau relationships are negatively affected by aphasia, the health and wellbeing of the whole whānau is likely to suffer.

In this context an investigation into the experiences of Māori with aphasia is warranted. The indivisibility of individual and whānau wellbeing (Love, 2004) suggests that such an investigation should involve whānau members as well as people with aphasia. The findings will guide clinical practice for SLTs working with Māori with aphasia and will provide a foundation for future research in this field.

**Methodology**

This study uses a KMR approach, incorporating the qualitative research methodology ID (Thorne, 2008). KMR is an Indigenous research approach that arose in response to research done on Māori subjects that privileged Western knowledge and disregarded Māori culture, language and knowledge. KMR cannot be summed up simply, but in essence it is “research for, by and with Māori” (L. T. Smith, 2012). ID is a qualitative descriptive method that is rooted in data and seeks to develop clinically relevant interpretive findings (Thorne, 2008).

An essential aspect of KMR is that the research benefits Māori, and the current study is no exception. One of the intended benefits is to increase SLTs’ understanding of the experiences of their Māori clients with aphasia, thus leading to more culturally appropriate and beneficial practices in the delivery of SLT services. SLTs are bio-medically trained, there are few Māori SLTs, and very few Māori service-providers that offer SLT services. Therefore, the vast majority of services for Māori with aphasia are delivered cross-culturally. If KMR is “research for, by and with Māori” (L. T. Smith, 2012), ID could be described as a methodology for, by and with clinicians. Bringing the two together is likely to make the research applicable to and understood both by Māori with aphasia and biomedically-trained non-Māori SLTs. A detailed analysis of the advantages and areas of tensions when using ID in KMR is provided in Chapter 3.

**Procedure**

This study received approval from the Northern Y Health and Disability Ethics Committee. As is common in KMR, this study was supported by a rangahau whānau. The group, which
was led by a kuia, approved the research plan and provided advice about participant recruitment, conducting interviews, and data analysis.

Participants
This study involved in-depth interviews with 11 Māori with aphasia and approximately 25 whānau members. Because “it is up to each whānau and each individual to define for themselves who their whānau is” (Minister of Health and Associate Minister of Health, 2002, p. 1), participants with aphasia nominated members of their whānau to participate.

The majority of participants in this study asked to be identified by their real names when quoted, and to be named in any acknowledgements. This practice was approved by the ethics committee. Participants were given pseudonyms if they requested this or if they were unable to consent to the use of their real names. Relevant details of participants are listed in Table 1.

Table 1 Relevant participant information

<table>
<thead>
<tr>
<th>PWA</th>
<th>M/F</th>
<th>Age range</th>
<th>TPO</th>
<th>Whānau members interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Makere</td>
<td>F</td>
<td>70-79</td>
<td>5+</td>
<td>2 daughters, 1 son</td>
</tr>
<tr>
<td>Noeline</td>
<td>F</td>
<td>70-79</td>
<td>2-5</td>
<td>daughter, son</td>
</tr>
<tr>
<td>Nan</td>
<td>F</td>
<td>70-79</td>
<td>&lt;2</td>
<td>6 daughters, 3 grandchildren</td>
</tr>
<tr>
<td>Connie</td>
<td>F</td>
<td>50-59</td>
<td>10+</td>
<td>husband, daughter</td>
</tr>
<tr>
<td>Christine</td>
<td>F</td>
<td>60-69</td>
<td>2-5</td>
<td>husband</td>
</tr>
<tr>
<td>Margaret</td>
<td>F</td>
<td>60-69</td>
<td>2-5</td>
<td>partner, brother</td>
</tr>
<tr>
<td>Jack</td>
<td>M</td>
<td>70-79</td>
<td>&lt;2</td>
<td>wife</td>
</tr>
<tr>
<td>Bobby</td>
<td>F</td>
<td>70-79</td>
<td>2-5</td>
<td>husband</td>
</tr>
<tr>
<td>Latimer</td>
<td>M</td>
<td>50-59</td>
<td>&lt;2</td>
<td>no whānau – SLT present to provide support</td>
</tr>
<tr>
<td>Hone</td>
<td>M</td>
<td>60-69</td>
<td>2-5</td>
<td>wife</td>
</tr>
<tr>
<td>Sam</td>
<td>M</td>
<td>60-69</td>
<td>2-5</td>
<td>partner</td>
</tr>
</tbody>
</table>

Note: Age range = years  
PWA = person with aphasia  
M/F = male or female  
SLT = speech-language therapist  
TPO = time post onset of aphasia (years)

Other demographic information
All participants had suffered at least one stroke and been diagnosed with aphasia by an SLT. At first, participants with aphasia were recruited through the first author’s personal
networks. This was an attempt to situate the research outside the public health system, and provide insight into the experiences of Māori with aphasia who did not receive SLT services. Coincidentally, the two people recruited via personal networks had received aphasia therapy through the public health system. After personal networks were exhausted, the majority of participants were recruited via SLTs. From their current or previous caseloads SLTs were asked to identify Māori with aphasia who might be interested in participating in the research. SLTs identified patients as Māori using the ethnicity data gathered by the DHB. Purposive sampling ensured variation in iwi (tribe), age, time post onset of aphasia, place of residence and living situation. Participants were from a range of iwi across the North Island of New Zealand. Seven participants with aphasia lived in cities and four in small towns. All but one of the participants lived with family members who cared for them to different degrees, ranging from 24 hour care to occasional assistance.

At the point at which they acquired aphasia, three participants were retired and one was not employed. One participant was studying part-time. The remaining six participants were employed in jobs including teaching, management, and manual work. After acquiring aphasia, only one participant returned to work; in a voluntary role at his previous workplace, a kura kaupapa Māori.

Pre-stroke, two participants were fluent speakers of te reo Māori and used the language regularly (both were teachers - one in a kohanga reo and one in a kura kaupapa Māori). A third participant had been a fluent speaker as a child but did not use the language much as an adult and a fourth used it only when praying. Of the two fluent speakers, one spoke te reo Māori better than English following the stroke and the other reported that aphasia affected both languages equally. Although some participants were bilingual, this study focused on their experiences of aphasia rather than their linguistic abilities (that is, this study does not attempt to address the complexities of bilingual aphasia).

Data collection
Data were collected via semi-structured interviews, 16 of which took place in the participants’ homes and one at a marae. All data collection was undertaken by the first author, an SLT experienced in working with people with aphasia. Interviews were undertaken in English, with some code-switching. The number of people involved in any given interview ranged from one to nine. Participants were offered the choice of being interviewed alone, as a whānau, or with other support people. All except one person with aphasia were interviewed with family members. Some family members were interviewed
alone because they were unavailable at the time of the whānau group interview. Open questions addressed the whānau’s experience of stroke, changes in communication following the stroke, and any other changes since the stroke. Participants were prompted to talk about changes in relationships, health, roles in family and community, spirituality, and activities. Interviews lasted between 45 minutes and 1 ½ hours.

Interviewing techniques were modified to enable participation of people with aphasia e.g. participants with aphasia were encouraged to write, draw, or gesture to convey their message, and the interviewer sought clarification and verification from the participant and family where necessary. Family members generally waited for the person with aphasia to respond as much as they were able before giving their own answers.

With the permission of all participants, interviews were audio recorded. For participants with aphasia who used a number of visual communication techniques, permission was sought to video record the interviews. One participant declined to be videoed. All interviews were transcribed by the first author. For those on video, details of the actions (e.g. facial expression, gesture, drawing) that added meaning were noted on the transcript. Paraphasias and apraxic errors were transcribed in the International Phonetic Alphabet and the transcriber’s interpretation of the meaning written in brackets e.g.:

I /ded/ [said] /dei/ [say] puts hand out, palm down, brings hand down sharply as if quietening someone, then sits up straight and points to self let me, whispers talk to me puts hand out towards husband, palm facing outwards, then back to own chest I can do it (Christine)

Data analysis
Data were analysed using an inductive approach. Transcripts were read and re-read by the first author, who then coded the data using NVivo10 software. As determined by ID, analysis moved from pieces to patterns and patterns to relationships (Thorne, 2008). That is, data analysis began with individual pieces of data (quotes). As patterns were recognised pieces were gathered together into “categories”. As analysis progressed, relationships between categories were created and categories came together in “themes”. Developing categories and themes were discussed at length between the first and second authors and checked with other members of the research team. As advised by ID, and appropriate for KMR, all participants were offered a return visit to discuss the developing findings. Five
whānau accepted a return visit and two requested a written summary. Revisited participants were very positive about the developing findings.

**Rigour**

When combining two research approaches, the requirements for rigour of both must be met. KMR and ID take rather different approaches to rigour, because they come from different paradigms. The main requirements for rigour in ID are epistemological integrity, representative credibility, analytic logic and interpretive authority (Thorne, 2008 pp.223ff.).

In order to have epistemological integrity the research question must be one that can be answered using ID and the data must be interpreted in keeping with the research question. ID studies address “pressing problems of [the researcher’s] disciplinary field” (Thorne, 2008, p. 51). Accordingly, this research addressed the question of Māori experiences of aphasia, which is highly relevant to the discipline of SLT in New Zealand. The existing beliefs and biases present within the discipline are acknowledged. Before interviews began the first author developed a written reflection about SLT and preconceived ideas about Māori and aphasia. This document was referred to after data analysis to ensure that the findings were not purely those that were listed from the beginning. Representative credibility requires that a study does not claim findings beyond the area in which data were collected. This study demonstrates representative credibility by acknowledging that the findings are representative of the 11 whānau who participated and cannot be expected to represent the views of all Māori whānau with aphasia. Analytic logic was achieved by the creation of an audit trail. The researcher kept notes throughout the interviewing and analysis process and saved multiple versions of the analysis as the categories and themes were being developed. Quotes from participants are provided throughout this article to illustrate how categories and themes were constructed. Interpretive authority was ensured by discussing coding and developing themes within the research team and with other colleagues.

KMR does not use the word “rigour”. Instead, emphasis is placed on how the research is conducted and what it aims to achieve. Two major requirements for KMR are that it is transformative and decolonising (Pihama, 2011). Transformative means that KMR aims to effect changes that will benefit Māori (Pihama, 2011). Before this project commenced, the rangahau whānau confirmed that it was likely to benefit Māori. Throughout the project ongoing approval was received from the rangahau whānau, participants, and in Māori and Indigenous forums. Being decolonising means that KMR studies privilege Māori knowledge and ways of knowing (L. T. Smith, 2012) and challenge dominant constructions of research
Throughout this project there were several occasions to challenge dominant constructions of research. When presenting aspects of this research we were frequently asked why there is no comparison group. The perception is that, in order for the findings of this study to be of value, the Māori participants must be compared to a non-Māori group to show what, if anything, is unique about Māori with aphasia. Expectations for a comparison group may be due to a lack of familiarity with qualitative research, which does not require a comparison group in the way that some quantitative research does. However, in the New Zealand context, there is an added dimension, as discussed by Cram (2001, p. 36):

In the past [Māori] have been mostly studied by outsiders (that is, non-Māori) and through this process we have been objectified as the “other”. The emphasis within such research has often been ethnocentric in that we have been compared with what have been described as universal, objective (read “Pākehā”) norms and found to be wanting. Our unique history, society and culture have often been disregarded in this process.

The dominant construction of research, with its tendency to study Māori as “other”, is likely to have contributed to requests for a comparison group. Given that this decolonising study was undertaken in a KMR framework, we were careful to study the experiences of Māori as Māori and not perpetuate the comparison to “universal” norms.

A more detailed discussion of the rigour and ethics of KMR and ID is provided in Chapter 3.

**Results**

As well as their aphasia, all participants spoke about the loss of other body structures and functions resulting from the stroke. Although data analysis focused solely on aphasia, it was impossible to fully separate the impact of aphasia in one’s life from the impact of the stroke overall. Moreover, the separation of aphasia from other stroke symptoms might not be appropriate for Māori. Comments from participants in this study suggested that they conceptualised everything related to the stroke as one entity. For example, Hone’s wife pointed out that Hone’s stroke affected his entire being, not just his language, “It’s not just the brain eh… It’s the whole āhua”. Āhua is one’s presence, being, or identity. This holistic approach is consistent with Māori views of health such as *Te Whare Tapa Whā* (Durie, 1998) and *Te Wheke* (Pere, 1984).
Participants described a diverse range of positive and negative experiences of aphasia. While there were many differences within and between whānau, there were also similarities. As described above, experiences of aphasia were divided into categories. The categories then developed into four interacting themes. The themes are in two pairs, with each pair addressing two approaches to the same situation. The categories and themes are connected like strands of flax that are woven into a mat (see figure 1). Although the flax strands (categories) start out as separate entities, they become closely connected as they are worked into the mat. The four themes are represented by the four sides of the mat, with pairs depicted opposite each other.

There is a particularly close relationship between the individual categories within the themes “Grieving for what is lost” and “Recognising what we’ve got”. These categories describe equal but contradictory experiences that were evident within individuals and within whānau. In the woven mat this relationship is illustrated by the categories being represented on opposite ends of the same pieces of flax. The categories within “It’s hard” and “Choosing how to respond” do not have a one-to-one relationship. Therefore, they are represented by separate pieces of flax.
Figure 1 The experiences of Māori with aphasia and their whānau are represented metaphorically in a mat which weaves together the complexity and diversity of life with aphasia.
“Grieving for what is lost” and “Recognising what we’ve got”

In the pair of themes “Grieving for what is lost” and “Recognising what we’ve got”, participants expressed grief for what had been lost due to aphasia, yet recognised what remained or had been gained since the stroke. Most often they not only recognised what they had, but were grateful for it. The concurrent feelings of grief and gratefulness created a tension which was evident within individuals and within whānau. Within this pair of themes we will focus on two salient pairs of categories. One pair is “tragic loss [of] language and communication” and “you count your blessings”. The other pair is “loss associated with a change in the role of the person with aphasia” and “no change in the status of the person with aphasia”.

The loss of language and communication is tragic but you count your blessings. For most of the participants the loss of language and communication was, as Makere’s son put it, “tragic”. A sense of loss permeated the interviews as participants spoke of the importance of language per se. Makere’s daughter explained, “For Māori, language is precious. And without it, we’re, well we are a bit lost I think. It is just the way the whole world ticks, through language and singing”.

Makere’s other daughter explained the importance of language for Makere’s iwi, “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”. These quotes illustrate how intertwined language and identity are for some Māori, and therefore the tragedy associated with the loss of language. However, not all participants shared or demonstrated this sense of loss. Latimer acknowledged his aphasia and the changes that it had brought, but for him it was not tragic. This was because, in contrast to Makere whose identity was centred on language, Latimer was still able to undertake his (largely nonverbal) hobbies and roles on the marae. While it was evident that aphasia was not a big problem for Latimer, Jack and Bobby both spoke very little about aphasia but their reasons for not speaking about it were unclear.

There is a counterbalance to the “tragic loss [of] language and communication”. As Connie’s daughter said, “you count your blessings”. While deploring all that they had lost, participants actively weighed up their situation against other possible scenarios. They kept the sense of loss in perspective by thinking of people who were worse off and remembering that the stroke could have been fatal.
Connie’s daughter summed up the interaction between considering the loss of language to be tragic, and counting your blessings. Although she felt like “Mum’s been robbed”, she bargained with herself that “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”.

**A change in role but no change in status**

The majority of participants with aphasia experienced some change in their whānau and community roles after acquiring aphasia. The extent to which people maintained their roles was a function of the nature of the roles and how dedicated the person with aphasia, whānau, and community were to preserving them. There was often a feeling of loss associated with changes in roles, as the person with aphasia missed being in their former role and whānau members missed the contribution of the person with aphasia. Despite feelings of loss, whānau members emphasised that the status of the person with aphasia did not change even when their role changed.

The change in role without a change in status created a sense of unsettledness for some whānau. When a person cannot fulfil their role, yet maintains their status, no-one else can take over that role. Makere’s daughter explained:

> When somebody dies and they’re not accessible anymore then … you can make solid adjustments. But … we’ve left a gap there because our mother’s still here, but she’s not able to fulfil the role that she used to, but we’re not prepared to put anything else in that place because that’s her job.

The interaction between a change in role and no change in status was most particularly evident when the person with aphasia was the matriarch of their whānau. In these situations the younger family members felt a strong sense of loss. Grown-up children and siblings spoke about the women maintaining matriarchal status but losing their ability to pass on knowledge or skills, run their whānau and provide the advice and emotional support that had been so important. In some situations daughters stepped up and took on elements of their mother’s role. However, they recognised that they could not do it as well as their mother, and that it would be frustrating for their mother to see that happening.

In maintaining the status of the person with aphasia, family members frequently emphasised that s/he was “still the boss”. Sam’s partner summed up the situation when she said “He’s still the man of the house… I just run it”. However, simply naming a person as the boss or
matriarch does not make them so. Whānau and communities need to demonstrate the person’s status by their actions. Hone’s community recognised his status by enabling him to continue his roles on the sports club committee, the marae committee, and at the kura kaupapa Māori. Although she was “quite scared”, Connie’s daughter continued to ask Connie to babysit her young children because she “wanted her to still feel like she was a competent grandmother”. Makere’s daughter did not take over her role of kaikaranga but enabled Makere to continue by making sure she only delivered the karanga in culturally-safe places.

“It’s Hard” and “Choosing how to respond”

In the pair of themes “It’s hard” and “Choosing how to respond”, participants talked about how hard life with aphasia is, describing a vast array of negative emotions. At the same time, participants demonstrated that they could choose how to respond to aphasia. Whānau did not just accept the “hard” situation, but they managed their emotional responses and actively managed recovery for the person with aphasia and whānau.

“It’s Hard”

Negative emotions

Negative emotions pervaded many of the interviews. The emotions do not belong in a category of their own but are part of all categories, woven throughout the whole experience of aphasia. This is demonstrated in figure 1 as the emotions are interspersed throughout the mat. The most strongly expressed emotions were sadness and frustration. Participants also spoke of shock, anxiety, burden (both the person with aphasia feeling that they were a burden and whānau members feeling the burden of the daily grind of caring), embarrassment, guilt, loneliness, and non-specific descriptions of “it’s difficult [emotionally]” or “it’s hard [emotionally]”.

Changes in intimate relationships

The onset of aphasia brought difficult changes in whānau relationships. The most significant changes were evident in intimate relationships. These included the relationship between the person with aphasia and their partner, and the primary carer’s relationship with their own partner.

When the partner of the person with aphasia became their carer there was a change in the dynamics of the relationship. Some partners-cum-carer took it upon themselves to anticipate
their partner’s needs, thereby minimising the likelihood of frustrating communication breakdowns. Partners of Sam, Christine, Margaret, and Jack talked about having to play the role of “interpreter” in interactions with friends and professionals. Sam’s partner was not happy that this arrangement made her party to conversations that she did not necessarily want to hear.

Separate from caring duties, aphasia caused other difficulties in relationships. Several wives found it distressing when aphasia caused their husbands to start swearing. On a deeper level, the partner of one man with aphasia suggested that, when asking about experiences of aphasia, one should ask about intimacy. She then pointed out that Māori would not usually talk about such things. This woman spoke about how they had not been as intimate since her partner’s stroke. She wondered whether this was a because of the stroke or because of her own health problems, but she did not know her partner’s thoughts on the subject. Many different health issues affect intimate relationships. The specific impact of aphasia is that couples cannot communicate on a deep enough level to discuss their situation. In this case the woman was unable to discuss their situation with her partner and therefore was left to worry about their relationship by herself.

Whānau members found different ways of balancing caring responsibilities with the needs of their own partner and family. It was hard for Nan’s daughter when becoming a fulltime carer brought about changes in her relationship with her own partner:

> I’ve been sleeping with Mum, and my partner stays here too so for seven months I’ve been with Ma while he’s in the other room... And I don’t go out no more unless it’s with Ma. My life revolves around Ma now. So me and him we don’t do things no more... like we used to

This led to Nan’s daughter feeling torn at times, although she told her partner “blood’s thicker than water” and stated that “he knows the rules”.

Makere’s children took turns to care for her in their family homes. By sharing and negotiating caring duties throughout shifting family circumstances, they worked to minimise the impact of caring on any one family or any one intimate relationship.

“Choosing how to respond”

Participants described their responses when faced with the “hard” situation of aphasia. They spoke about the deliberate conscious ways that they determined to cope, and alluded to not-
so-deliberate ways of managing their own responses and managing recovery for the person with aphasia and the whānau.

**Managing emotional response**

Laughing and joking about paraphasias and communication breakdowns were common ways to manage emotional responses, as was resolving to move forward one step at a time. Some people gained emotional support from their faith in God. Sam’s wife explained, “[My faith] has helped me. Oh I don’t think I could handle any more if I didn’t have that”.

Noeline’s daughter tried to help her siblings cope, “we just gotta see how things go… Because this isn’t the end, it’s just a different beginning”. Some coping strategies were negative. Christine’s husband explained that Christine’s extended family “didn’t know what to say” so they avoided talking to her. Many families found lability distressing so would avoid situations in which the person with aphasia might become labile. Margaret’s brother went to great lengths to do this. He organised a surprise party for Margaret’s birthday but he told her about it in advance, in case the surprise caused her to become emotional. Margaret then had to pretend to be surprised.

Many people responded to aphasia by being positive. This appeared to be a way of coping emotionally. As participants spoke of their positivity it was evident that at times they genuinely felt positive, e.g: Connie’s daughter said “I don’t feel like anyone should be sorry for me ‘cos I’ve still got my Mum”. Sometimes the positivity was a deliberate resolution, e.g: Noeline’s daughter said “We’ve gotta try and have faith… for ourselves and for her” and Christine’s husband said “I don’t let aphasia worry us”. At other times it appeared that participants were saying that they were positive in an attempt to make it come true, e.g: Hone’s wife said “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”.

When faced with communication difficulties and embarrassment, some people with aphasia withdrew. There was an increase in time spent at home and time spent alone, and an avoidance of conversations. For the very social people this was a big change, but for the more introverted it was an extension of how they were inclined to be anyway. Reasons for withdrawing included the inability to speak to people, embarrassment, lack of transport, and a reduced number of friends. Margaret described how she would prefer to play games on her computer because it was easy, “You can do it all day, and nothing will faze you”. However, she recognised that “I have to, make the effort, to um communicate”. Christine explained
how while she was in the rehabilitation ward she refused to go to the dining room to eat because she could not converse with anyone:

Christine: **I had kai** (food) **one ah ah um the gestures a horizontal square in front of her but now um ah everybody kai** (eat)

Husband: The dining room?

Christine: **Yeah. I shakes head I didn’t want do /kn’d/ [‘cos] I couldn’t brings hand to mouth then gestures outwards, indicating speech … Everybody said da da da hand to mouth indicating speech /mAbi/ [but me] hand on chest I couldn’t**

**Managing recovery**

When managing their recovery from stroke, whānau members demonstrated that they accepted responsibility for the wellbeing of the person with aphasia, and for communication with and for them. Hone’s wife explained the root of this when she stated “he’s a part of us” and “we’re responsible for each other”.

**Accepting responsibility for the wellbeing of the person with aphasia**

Taking responsibility for the wellbeing of the person with aphasia manifested in several ways. At a basic level it entailed taking responsibility for their health and personal safety, praising their achievements, and providing for their basic needs. In some families there was tension around the latter point when some family members showed their care and concern by encouraging the person with aphasia to increase their independence while others showed it by doing everything for them. Family members also took responsibility for organising leisure activities and social events and actively preventing the person with aphasia from withdrawing.

At a deeper level, family members considered their own behaviour and its impact on the person with aphasia. They often took responsibility for resolving stressful family situations in order to protect him/her. Family members were determined not to burden the person with aphasia. This often meant putting his/her needs ahead of their own. Nan’s daughter hinted at how difficult this was when she said “Just let her enjoy as much as she can. I don’t care what I’ve gotta go through… I need to stop and think like that”.

**Accepting responsibility for communication**

Whānau members demonstrated that they accepted responsibility for communicating with the person with aphasia and for that person communicating with others. It was common for whānau members to blame themselves for not understanding or for not enabling the person
to express him/herself. They seldom placed emphasis on errors made by the person with aphasia. Nan’s daughter expressed this, “She knows what she wants but it’s us that we don’t know. And it takes us a long time sometimes to get it”. Makere’s son said that when communication breaks down “I feel quite inadequate about it all”.

Whānau members endeavoured to change their own language, behaviour, or demeanour to enable the person with aphasia to communicate. This included an emphasis on spending time together, slowing down, and persisting until the message had been communicated. Nan’s daughter explained “It’s just having a lot of patience… and not rushing her either ‘cos it takes time for her to think…and put her memory into her voice”. Noeline’s son emphasised the importance of being together when he said “I’m always busy and doing whatever but having to sort of sit down and stop and look kanohi ki te kanohi (face to face)… and just to talk and spend the time”. Some whānau learnt these techniques from their SLT, while other whānau had to work them out independently.

Changing one’s own behaviour is not easy, as Hone’s wife admitted, “We’ve learnt patience is a virtue. Patience, ah man, run out of that too”. Whānau members also accepted responsibility for initiating social contact, pre-empting what the person with aphasia might want to say, carrying the conversation, involving the person with aphasia in the conversation, and keeping the conversation on track.

**Summary of results**

For the participants in this study there were positive and negative experiences of aphasia. Many of the negative elements were inevitable, e.g. negative emotions and loss of the ability of the people with aphasia to continue their roles. People with aphasia and whānau demonstrated that they can choose how to respond to their situation and their response can improve the situation or make it worse.

**Discussion**

This study aimed to describe and interpret the experiences of Māori with aphasia and their whānau, to begin to inform service delivery for this population. As KMR, this study makes no attempt to compare Māori and non-Māori experiences of aphasia or to highlight what is “unique” about Māori with aphasia. However, the findings will be considered in the context of the existing aphasia literature.
For many, but not all, Māori with aphasia, the loss of language and communication was tragic and brought with it various negative emotions. Some of the experiences echoed those already documented in the literature. Grief was often mitigated by being grateful that the person with aphasia was alive (Brown et al., 2010) and recognising that others were worse off (Cruice, Worrall, & Hickson, 2006a). Participants found ways of managing their emotions such as deliberately being positive (Michallet et al., 2003) and “striving for a positive way of life” (Brown et al., 2010). They did not necessarily feel positive but they deliberately tried to be positive. There were, however, a few participants who did not speak of aphasia being tragic, instead focusing on other aspects of their lives and identities. Armstrong et al. (2012) described a similar response from all three of their Aboriginal Australians participants, who spoke little about their aphasia even when asked. The researchers proposed three possible reasons for this apparent lack of concern about aphasia – other health issues being more salient, the long time post-onset of aphasia leading to aphasia being part of the person’s identity rather than a separate condition worthy of discussion, or a cultural construction of disability in which communication disorders are not identified discretely. The first two reasons did not appear to be relevant to the participants in the current study. However, as observed at the beginning of the results section, there was some indication that participants might not perceive aphasia as a discrete disorder.

Participants in this study experienced many changes when the person with aphasia was no longer able to fulfil their role in the whānau and/or community. The aphasia literature shows that when a person with aphasia is not able to continue in their role, family members often take it on (Grawburg et al., 2013a; Michallet et al., 2003). While children of Māori with aphasia can take on some of their parent’s roles, it is not always appropriate for them to do so. In Māori society, if a child takes over their parent’s role on the marae while the parent is still alive it may diminish the parent’s mauri (Rangihau, in King, 2011). Participants in this study made it clear that, regardless of any changes in role, there was no change in the status of the person with aphasia. Māori tend to recognise one’s context in assigning status - context being whakapapa and actions/behaviour - and role determined by their status and their skill set. We are not aware of any existing aphasia research discussing this phenomenon. Le Dorze and Brassard (1995) identified “giving up the role of imposing one’s authority on the family” (p.248) as a coping strategy used by people with aphasia, but this does not appear to be pertinent for Māori with aphasia. There was no indication that the Māori with aphasia in this study had ever imposed their authority on the family, rather it
was given to them. The status of the person with aphasia endured aphasia-related role changes and was reinforced and encouraged by whānau members.

Previous studies (Grawburg et al., 2013a; Hallé et al., 2011) have shown that family members take responsibility for the wellbeing of a person with aphasia by endeavouring to protect them. Several examples from the literature were also evident in the current study. These include children seeking parental support from people other than their parent with aphasia (Grawburg et al., 2013a), not sharing stressful situations (Hallé et al., 2011), and acting on behalf of the person with aphasia (Hallé et al., 2011). For this group of Māori with aphasia there was a deep, almost spiritual, reason for taking responsibility for the wellbeing of the person with aphasia. That is, the indivisibility of individual and whānau wellbeing (Love, 2004), which Hone’s wife described as “he’s a part of us”.

In a related area, whānau members described taking responsibility for communication with and for the person with aphasia. This concept is well established in the literature (Croteau & Le Dorze, 2006; Grawburg et al., 2013a; Le Dorze & Brassard, 1995). Croteau and Le Dorze (2006) linked “speaking for” to “overprotection” and determined that it would have a negative impact on the communication of the person with aphasia. Participants in the current study acknowledged that “speaking for” is not always a good thing, e.g. Makere’s daughter said:

While that serves a purpose, we also know that it’s not good because we’re really narrating her space as opposed to her narrating that herself

However, on the whole they did perceive “speaking for” behaviours as negative or over protective, but as a (not always ideal) means of facilitating communication.

When taking responsibility for the communication of the person with aphasia, a fundamental difference was evident between the attitudes of whānau members in the current study and the attitudes of family members reported in the literature. Le Dorze and Brassard (1995) reported that relatives felt irritated when they could not guess what the person with aphasia meant and thought that s/he did not give enough information to be understood. In contrast, whānau members in the current study expressed feeling inadequate when they could not understand the person with aphasia, emphasising their own deficiency in understanding. The feeling of irritation places the responsibility for communication on the person with aphasia whereas the feeling of inadequacy places the responsibility for communication on the family member.
Experiences of aphasia are “shaped by cultural practices and the world views” (Legg, 2010, p. 240). In aphasia, as in life, there are both similarities between cultures and differences within cultures. This was true of Legg’s South African participants, Armstrong et al.’s (2012) Aboriginal Australian participants, and the Māori participants in this study. Indeed, it is true of all people with aphasia. Although most aphasia research does not claim to pertain to a particular culture, it is always shaped by the culture and world views of the participants and the researchers.

Strengths, limitations and clinical implications

The most appropriate way to address Māori health issues, such as aphasia, is to do so from a Māori perspective. Therefore, a strength of this study was the use of KMR. The political and ethical guidance provided by KMR ensured that the research was relevant and undertaken in a way that was culturally appropriate. The combining of KMR and ID makes the research applicable to and accessible for a wide range of Māori with aphasia and clinicians.

There are strengths and limitations inherent in interviewing whānau groups. Interviewing whānau groups provided support and assistance with communication. It also gave family members a chance to talk about their experiences and hear each other’s stories. However, it is likely that the participants shared differently because they were in a whānau group and may not have felt comfortable saying certain things. Connie’s daughter explained:

> It’s actually hard talking about Mum with Mum in the room. Like we talk… about her … and our frustrations when she’s not around but we don’t want to hurt her by talking about it when she is around

A limitation of this study is that all participants had received SLT at some stage. It would have been beneficial to include people who had not received SLT input. This would have provided valuable insight into the situations in which Māori with aphasia do not receive SLT services. However, it is difficult to make contact with such people because they are not connected to the health system.

This is the first time that research has been undertaken specifically focusing on Māori with aphasia and their whānau. Therefore, there are many clinical implications of this study but further research is necessary before the findings can be applied directly. The next step is to consult Māori with aphasia, whānau members and SLTs, seeking their advice about how to use the findings in SLT for Māori with aphasia.
Conclusion

This study provides insight into the experiences of Māori with aphasia and their whānau. It shows that aphasia can have a profound effect on Māori families and bring many negative emotions and changes in relationships. In these difficult circumstances, whānau actively decide how to control their emotional response and direct recovery. Because of the inseparability of individual and whānau, whānau members tend to accept responsibility for the wellbeing and communication needs of the person with aphasia. Whānau and community members can support a person to continue in their roles despite aphasia. Even when a role change is inevitable, they can work to ensure there is no accompanying change in the status of the person with aphasia. As the first research to be undertaken with Māori with aphasia and their whānau, this study has only begun to explore their experiences. The true applicability of these findings will be revealed by taking them to Māori with aphasia, whānau members, and SLTs and combining their knowledge and experience to inform SLT service delivery.

References


Chapter 5: “But I’m from Hauiti and we’ve got shags”: Māori experiences of aphasia therapy


This publication is inserted as submitted for publication, with the exception of minor edits and formatting changes to maintain consistency throughout the thesis.
Abstract

In this kaupapa Māori research study we explored Māori experiences of aphasia therapy, and how these experiences might inform an accessible, culturally appropriate and culturally safe SLT service for Māori with aphasia and their whānau (extended family) members. Interpretive description (a qualitative methodology) was incorporated within the kaupapa Māori research approach. In-depth semi-structured interviews were undertaken with 11 Māori with aphasia and their nominated whānau members. They reported a wide variety of experiences of aphasia therapy, in six themes: We’re happy to do the work, but we can’t do it alone; Relationship; Our world view; The speech-language therapy setting; Aphasia resources; and Is this as good as it gets? While some services were reportedly accessible and culturally appropriate for Māori with aphasia, others were not. We conclude that for Māori with aphasia, a strong therapeutic relationship is central. The success of this relationship is shaped by the SLT’s appreciation of the world view of the person with aphasia and whānau, the setting of the therapy and the resources used. Successful therapy will involve collaboration between clinician and whānau, and therapy resources that affirm the identity of the person with aphasia.
Health services should be “respectful of the culture of individuals, minorities and indigenous populations” (World Health Organization, 2001b, p. 12). Within the New Zealand context, the NZDS (Minister for Disability Issues, 2001) expands on this further. Objective 11 of the strategy (Minister for Disability Issues, 2001, p. 25) aims to “promote participation of disabled Māori” (the Indigenous peoples of New Zealand) in all aspects of society, including health and disability services. The strategy calls for mainstream providers of disability services to be “accessible to and culturally appropriate for disabled Māori and their whānau” (extended family). For people with aphasia, the SLT is key in health and disability service provision, and most SLTs work for “mainstream providers”. The extent of the knowledge, understanding and humility required to provide culturally appropriate and safe services for Māori with aphasia is illustrated in the title of this article; a quote from Makere, a Māori elder with aphasia. When Makere was given a reading passage about ducks in New York, as part of her SLT session, she informed the SLT that her home town (Hauiti) has shags (not ducks). Makere’s eloquent expression of the need to incorporate her environment and world view in therapy sessions underpins this article.

At present SLTs have little guidance as to what constitutes an accessible, culturally appropriate, and culturally safe service. There is no published research involving Māori with aphasia (McLellan et al., 2011). In the absence of directly relevant literature, we can seek direction from the Māori and Indigenous health and disability literature and the existing (non-Māori) aphasiology literature. These have shown areas in which current service provision is inadequate, inappropriate, and/or in need of improvement (e.g. Arlidge et al., 2009; Armstrong et al., 2012; Harwood, 2012; Hersh, 2009; Parr, Byng, Gilpin, & Ireland, 1997; Wiley, 2009). In this context, it is unlikely that Māori with aphasia find SLT services are entirely accessible, culturally appropriate nor safe. In light of this, the current study explored Māori experiences of aphasia therapy, in order to determine what an accessible and culturally appropriate service might look like and how it might be achieved.

The only existing description of Māori experiences of SLT following stroke is that provided by Harwood (2012), who gave two examples. The first was from an elder who observed an SLT working with a Māori patient. The elder observed that the patient struggled to understand and pronounce the English words that the SLT was using, but understood well when the elder spoke to him in Māori. The second example was from the daughter of a man who did not receive SLT input after his stroke. She recognised that her father would have adjusted better to living with stroke if he had received SLT early on. These two examples
give some insight into Māori experiences of SLT. That is, therapy is not always provided in the language in which Māori need it or at the time at which Māori need it.

As part of an outcome evaluation of Objective 11 (Minister for Disability Issues, 2001) Wiley (2009) interviewed Māori with disabilities and their caregivers. Participants reported having to compromise their Māori world view to access mainstream services because service providers did not acknowledge their culture or take care of their cultural needs. Furthermore, consumers and caregivers needed to be “extremely proactive, even aggressive” (Wiley, 2009, p. 1210) to access services and had to find their own way through the system to get the assistance they required. The caregivers of Māori children admitted to hospital have also identified a lack of cultural awareness among staff and the need to be proactive in order to access services (Arlidge et al., 2009). In Arlidge et al.’s study many caregivers were not able to be proactive because they were “alienated within the hospital environment … and did not appear to see themselves as being entitled to high-quality information or services” (Arlidge et al., 2009, p. 177).

It is well documented that the therapy setting, resources used and the relationship with the SLT are all important for the success of aphasia therapy (Armstrong et al., 2012; Fourie, 2009; Hersh, 2004, 2009; Parr et al., 1997). Preferences for environmental setting, relevance of resources used in therapy and the nature of the therapeutic relationship are all shaped by a person’s culture. Therefore, SLTs working with Māori need to be aware of ways in which Māori culture might influence these aspects of therapy. With the dearth of literature about Māori experiences of aphasia and language therapy, one could look to other Indigenous populations for direction. However, there is very little research about aphasia in any Indigenous peoples (Armstrong et al., 2012). From their research with Aboriginal Western Australians with aphasia, Armstrong et al. (2012) highlighted at least one area that might be applicable to service delivery for Māori with aphasia. They observed that their participants were active in community groups and might benefit from language therapy or aphasia education being integrated into these existing groups rather than provided as a separate service.

In light of the situation outlined above, the aim of this study was to explore Māori experiences of aphasia therapy, with a view to ascertaining what constitutes an accessible and culturally appropriate service and how it could be achieved.
Methodology

In the current article we expand on the findings from a larger study about the experiences of Māori with aphasia and their whānau. This is a KMR study. KMR is an Indigenous research approach that is, in essence, “research for, by and with Māori” that privileges Māori knowledge and ways of knowing (L. T. Smith, 2012, p. 185). Kaupapa Māori theory is a “theoretical position” within the critical theory framework (Pihama, 1993, p. 39). Using this critical approach, KMR always involves “an analysis of existing power structures and societal inequalities” (Pihama, 1993, p. 56). Therefore, all aspects of this research involved a critical approach and an analysis of power. The qualitative research methodology ID was incorporated with KMR. ID is rooted in a discipline (in this case, SLT) and is used to develop clinically relevant findings (Thorne, 2008). KMR and ID both focus on applied research that will benefit the community in which it is undertaken. The combination of KMR and ID ensured that the research was relevant to Māori and to SLTs and likely to benefit both groups.

Procedure

This study was approved by the Northern Y Health and Disability Ethics Committee. In keeping with KMR, it was guided by a rangahau whānau. The rangahau whānau in the current study was a group of Māori with a connection to stroke, led by a kuia. They provided guidance for the research plan, participant recruitment, researcher conduct, and data analysis.

Participants

Participants were 11 Māori with aphasia and 23 whānau members. Initially, participants with aphasia were recruited through the first author’s personal networks. All had been diagnosed with aphasia by an SLT following a stroke. When personal networks were exhausted, recruitment continued through SLTs. Individuals with aphasia nominated the family members they wished to participate. Most of the participants in this study asked to be acknowledged by name in the text and in the acknowledgements section. This practice is not unusual in KMR but would be considered a violation of participants’ rights to anonymity in a non-Indigenous research framework. It was discussed with the rangahau whānau and then approved by the ethics committee. Pseudonyms were used when requested or for participants who were unable to consent to the use of their real name. Relevant participant information is listed in table 2.
Table 2 Relevant participant information

<table>
<thead>
<tr>
<th>PWA</th>
<th>M/F</th>
<th>Age range</th>
<th>TPO</th>
<th>Rural/urban</th>
<th>Speaks te reo Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connie</td>
<td>F</td>
<td>50-59</td>
<td>10+</td>
<td>Urban</td>
<td>No</td>
</tr>
<tr>
<td>Latimer</td>
<td>M</td>
<td>50-59</td>
<td>&lt;2</td>
<td>Rural</td>
<td>No</td>
</tr>
<tr>
<td>Christine</td>
<td>F</td>
<td>60-69</td>
<td>2-5</td>
<td>Urban</td>
<td>No</td>
</tr>
<tr>
<td>Margaret</td>
<td>F</td>
<td>60-69</td>
<td>2-5</td>
<td>Urban</td>
<td>No</td>
</tr>
<tr>
<td>Sam</td>
<td>M</td>
<td>60-69</td>
<td>2-5</td>
<td>Rural</td>
<td>No</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>
</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>
</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>
</tr>
<tr>
<td>Noeline</td>
<td>F</td>
<td>70-79</td>
<td>2-5</td>
<td>Urban</td>
<td>Only when praying</td>
</tr>
<tr>
<td>Nan</td>
<td>F</td>
<td>70-79</td>
<td>&lt;2</td>
<td>Urban</td>
<td>No</td>
</tr>
<tr>
<td>Jack</td>
<td>M</td>
<td>70-79</td>
<td>&lt;2</td>
<td>Urban</td>
<td>No</td>
</tr>
</tbody>
</table>

Note: Age range = years
- PWA = person with aphasia
- M/F = male or female
- TPO = time post onset of aphasia (years)
- rural/urban = where the participant lives
- te reo Māori = the Māori language

Other demographic information

All but one participant lived with family members who provided varying degrees of care and support. Six participants were employed at the time they acquired aphasia. Of these, only one returned to work; volunteering at the kura kaupapa Māori (Māori immersion primary school) where he had previously been employed. All participants had received SLT. Some were still receiving therapy at the time of their interview.

Data collection

Data collection involved semi-structured interviews with individuals or whānau groups. Participants were asked about the stroke, its impact on communication and the impact of the changed communication on their lives. When the first two whānau spontaneously mentioned the topic of SLT, it became evident that SLT might be an important part of the experience of aphasia. Consequently, we included questions about participants’ experiences of language therapy in subsequent interviews.

Interviews were undertaken by the first author, an SLT with experience in aphasia. Participants chose the locations for the interviews. One interview took place at a marae and
the remaining 16 in participants’ homes. All interviews were conducted in English, although participants often used Māori words and phrases (as is common practice in New Zealand English vernacular). Participants with aphasia determined who attended their interviews. Most were interviewed in whānau groups, although one was interviewed alone and one with his SLT as a support person. Family members who were unable to attend their whānau group interview were interviewed separately. Interviews lasted 45 minutes to 1 ½ hours. The interviewer and whānau members assisted participants with aphasia to participate in the interviews by encouraging them to use writing, gesture, or drawing to enhance their communication. Family members clarified the response of the person with aphasia as required, and then added their own answers. All interviews were audio recorded and transcribed by the first author. Consent was sought to video-record interviews if the person with aphasia used a lot of visual supportive communication techniques. One such participant did not consent to be videoed.

**Data analysis**

Data analysis followed an inductive approach, informed by ID (Thorne, 2008). The first author read and re-read the transcripts and then coded them using NVivo10 software. As individual quotes were coded, patterns emerged and the quotes were gathered together into themes. As analysis progressed, relationships between themes became evident. Developing themes were discussed at length within the research team. As is appropriate for KMR, and recommended by ID, all participants were offered a return visit to discuss the emerging analysis. All available whānau received a return visit, with some others requesting a written summary instead. Participants were very positive about the emerging analysis.

**Rigour**

KMR and ID take rather different approaches to rigour, because they come from different paradigms. When these two research approaches are combined, rigour requirements of both must be met. The word “rigour” is not used in KMR. Instead, KMR places emphasis on being decolonising and transformative (Pihama, 2011). In decolonising research Māori have control over Māori knowledge and investigations into Māori issues (Cram, 2001). In this study, whānau have retained control over their data with one whānau reserving the right to check all reports before dissemination. Transformative means that KMR aims to make a positive change for Māori (Pihama, 2011). Before data collection began, the rangahau whānau confirmed the expected benefits for Māori from this project. On-going approval was received from various sources including the participants and Māori and Indigenous forums.
The main requirements for rigour in ID are epistemological integrity, representative credibility, analytic logic and interpretive authority (Thorne, 2008, p. 223ff). In order to have epistemological integrity, the research question must be congruent with the stated epistemology, and data must be interpreted in keeping with the research question. ID studies address problems recognised within the discipline (Thorne, 2008). Accordingly, in this research we investigated Māori experiences of aphasia therapy, recognising that this information is important for the discipline of SLT in New Zealand and other countries where Māori live. As a way of acknowledging the existing beliefs and biases within the discipline, the first author developed a written reflection about Māori and aphasia therapy before interviews began. After data analysis, this document was re-read to ensure that the findings were not preconceived. Representative credibility requires that claims about findings are consistent with the sampling that was undertaken. We gained representative credibility by acknowledging that the findings of this study come from the views of the 11 whānau who participated. They are not representative of all Māori whānau with aphasia. Analytic logic came from creating an audit trail throughout the interviewing and analysis process, and providing quotes from participants to illustrate claims. Interpretive authority was assured by checking analysis with members of the research team and other colleagues.

**Results**

Participants reported a wide range of experiences of aphasia therapy. Some experiences were positive and some were negative. Some were memorable and others eminently forgettable (requiring prompting to recall any detail). Time post onset of aphasia did not appear to influence people’s attitudes towards the therapy they had received or hoped to receive. There were many stories of language therapy meeting people’s various needs. Margaret and Noeline spoke of their SLTs helping to solve problems with communication, while Hone’s wife and Sam’s partner valued therapy outpatient appointments as opportunities for the men to have an independent outing. At times, critical evaluation of participants’ experiences of language therapy revealed inadequacies in a service with which the participant had expressed satisfaction. That is, participants were happy with the service they received but, like the participants in the study of Arlidge et al. (2009), this was because they did not know that they were entitled to anything better. Of all the participants, Makere’s whānau spoke the most about speech language therapy. They critically appraised the services they had received and made suggestions for improvements. The whakaaro and kōrero of this whānau have made a particularly valuable contribution to the research.
From the data of experiences of aphasia therapy six themes emerged. Two themes pertaining to the *context* of therapy and four pertaining to the therapy itself. The themes are listed in table 3.

**Table 3 Themes**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>We’re happy to do the work, but we can’t do it alone</td>
<td>Context</td>
</tr>
<tr>
<td>Relationship</td>
<td>Therapy</td>
</tr>
<tr>
<td>Our world view</td>
<td>Therapy</td>
</tr>
<tr>
<td>The speech-language therapy setting</td>
<td>Therapy</td>
</tr>
<tr>
<td>Aphasia resources</td>
<td>Therapy</td>
</tr>
<tr>
<td>Is this as good as it gets?</td>
<td>Context</td>
</tr>
</tbody>
</table>

The relationship between these themes is depicted in figure 2 and an explanation of the figure follows.

**Figure 2** Māori experiences of aphasia therapy

The therapeutic relationship between SLT, person with aphasia, and whānau is central to the success of aphasia therapy. This relationship is directly and indirectly influenced by the degree to which the SLT appreciates the world view of the person with aphasia and whānau. This can only happen if the SLT first appreciates his/her own world view. Directly, the recognition of world view shapes the way clinician and clients interact during therapy encounters. Indirectly, it influences the setting of the therapy and the resources used, which in turn shape the relationship. In addition, the therapy setting and resources independently
influence the therapeutic relationship. In this model, therapy setting and resources are external factors, which are often dependent on funding and processes outside the SLT’s control. In contrast, the appreciation of world views is dependent on the SLT’s attitude and experience. This internal factor requires reflective practice, which is limited only by the SLT’s time and motivation.

The therapy context has two themes. Entering into therapy, participants demonstrated that they took responsibility for the rehabilitation of the person with aphasia, but that they needed the guidance of an SLT (“We’re happy to do the work but we can’t do it alone”). Emerging out of the therapy experiences is the question “Is this as good as it gets?” In this theme, whānau reflected on the therapy they had received and whether they would benefit from more therapy.

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

In entering the aphasia care pathway many whānau members felt that language therapy was their responsibility and they were prepared to put a lot of time into language rehabilitation exercises. However, whānau were often frustrated by a lack of information about aphasia and how they could best support or provide rehabilitation. Sam’s partner acknowledged her responsibility for Sam’s rehabilitation and saw professional support as an appreciated extra, “Thank goodness for ones like [SLT] and all them … for him to get that extra care because sometimes family can’t do that. There’s so much for family… to have to take care of”.

Christine and her husband took a very active part in SLT and, as her husband said, “we really worked- she really worked hard”. They spoke about spending six or seven hours a day on speech and language exercises during her three months in hospital, both with the SLT and by themselves.

While taking responsibility for language rehabilitation, participants recognised their need for professional guidance. Participants placed high value on SLT involvement but not everyone received the support they needed. Margaret’s brother said:

> We would have liked to have known what some of the good exercises could be so that we could do them, ‘cos we spent a lot of time at the beginning with her really not knowing what to do

Makere’s daughter said:

> There is so much value for Māori people in learning how to cope after strokes, if we understand speech-language therapy techniques, and understand what they’re for...
We could have had Mum back at a better level earlier if we had understood the process a bit better.

Makere’s whānau did everything they could, even when they did not always understand why, as her daughter explained:

We couldn’t understand why they wanted Mum to poke her tongue out. But we dutifully found out that these were the exercises our mother had to do so we got the set of exercises and we made our mother practise them … It’s not, sort of eight years later that I realise personally that there were two aspects to it. That you had paralysis in your tongue and down your throat as opposed to the speech comprehension going on in the brain.

These quotes show that Margaret’s and Makere’s whānau accepted responsibility for rehabilitation. They required education and guidance from the SLT, but they did not receive this. They lacked information about aphasia, the role of the SLT, and the rehabilitation process.

**Relationship**

The SLT’s relationship with the person with aphasia and whānau is the key to aphasia therapy. It has a profound impact on the success of therapy and satisfaction with therapy. Several participants spoke fondly of their SLTs, although they were not always able to recall exactly what had happened in therapy. Bobby described her SLT as “really neat”, but, after being reminded that she had in fact received therapy, she could only remember it as “er lot of er talking”. Noeline’s daughter described the SLT as “so cool” and Jack said his SLT was “ah good ah helping me”. Christine also spoke highly of her SLT:

Christine:
She good, a lady was good to me

Interviewer:
Is that the speech therapist?

Christine:
Yeah *nods*. Yeah.

Nan and Makere had contrasting experiences of the therapeutic relationship. Together they demonstrate the impact of relationship on language therapy. Nan received therapy at a University clinic, where she had a very good relationship with the SLT students. Nan’s
family would joke that she was going to university to get a diploma, so the students presented her with a certificate at the end of the block of therapy. Nan valued the certificate highly and her children had it framed and placed on the family wall. Nan and her whānau appeared to value the trip to the university and the relationship with the student therapists above the content of the therapy sessions. One daughter, however, commented that “Ma’s getting bored” and another said “We’re not sure whether we’re going to go again”, despite Nan being less than one year post-stroke and on her second short block of therapy. These comments suggest that Nan’s relationship with the student therapists was vitally important for her receiving language therapy. If she had not valued the relationship so highly she might not have attended therapy for as long as she did.

There were many difficulties in the relationship between Makere and her SLTs. The root of the problem was that the SLTs did not acknowledge Makere’s language, world view and intelligence, and did not enable her and her whānau to understand what SLTs do and why. Makere’s son described the resulting situation:

    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”… but we’d take her up there and she was very much disinterested.

An additional problem for Makere was that she experienced a change of therapist during her block of therapy. Her son said this took them “back to square one”.

The contrasting experiences of Makere and Nan reveal much about the therapeutic relationship. Nan’s story demonstrates that a good relationship with the SLT can motivate people to continue receiving therapy even when they do not want to. Makere’s story demonstrates that even if the person with aphasia and family are internally motivated, they are unlikely to want to attend therapy sessions if the relationship with the therapist is not good.

**Our world view**

The recognition of world view is extremely important for the therapeutic relationship and therefore the success of aphasia therapy. Many of Makere’s difficulties with SLT stemmed from her culture and world view not being recognised. Makere spoke te reo Māori and English before her stroke. After the stroke her Māori language was much better than her English. Unfortunately, Makere did not have access to therapy in te reo Māori and the SLT did not recognise when she was answering correctly in Māori. Her son gave an example:
The speech therapist didn’t even consider that Mum would probably be better with cue cards that were in Māori. You know, she keeps showing “dog”, turn the card over it says “dog” on the back, picture of a dog. Shows it to Mum, Mum goes “kurī”(dog) and then [SLT] goes “no, dog”.

Makere’s family arranged for an interpreter to come to therapy sessions but that was not very successful either. Her daughter explained that, because the interpreter only interpreted words and did not explain world views, Makere’s answers were interpreted as incorrect:

The concepts that the speech therapist was looking at were, um, Mum was translating them into a Māori framework and then replying in that framework, but I can see that it would be interpreted as a cross

This situation illustrates an important, but often overlooked, concept. The therapy was not only in an English medium, it was in the accompanying Pākehā world view. In Makere’s therapy sessions the interpreter was translating the words but Makere had to translate the concepts. The presence of a kaitiaki Māori (Māori support worker) at SLT sessions did not help either. Makere’s daughter explained, “Mum would be giving it in Māori and [the kaitiaki] would be going ‘mmm’ and … they had the same understanding that our mother’s answered the question right”. However, the SLT, who was in control of the therapy session, still did not understand that Makere had answered correctly. Therefore, Makere did not have the opportunity to demonstrate her ability.

Makere’s son reinforced this point when he described having to “jump through all the hoops” to get help for his mother. A process he described as having “no Māori-ness about it”. He reflected on whether he should have asked the SLT to provide Māori therapy resources, “I don’t know where you draw the line between Māori things and what should happen in a Pākehā world or Westerner world”. This quote shows that, because the health system had “no Māori-ness about it”, Makere’s son wasn’t sure if he could expect, or even ask for, Māori content in the therapy sessions, even when he knew that would be best for his mother.

**The speech-language therapy setting**

Participants described various therapy locations and how these had the potential to either enhance or diminish their aphasia therapy experiences. The setting of the therapy contributed directly to the therapeutic relationship and influenced the kind of therapy that could be delivered. Makere had to attend a hospital clinic for aphasia therapy because there was no community service in her area. She found the clinic environment detrimental to the
therapeutic relationship and a barrier to participating in therapy. Her son suggested an approach that would have been preferable, “You could’ve got around it a lot easier as a speech therapist if it was conversational and there was a fairly relaxed environment - lounge or kitchen, a cafe or anything but an office”.

At the time of Hone’s interview he had been going to weekly therapy at a hospital clinic for over four years. It was a positive experience for him and he valued the exercises done in the therapy sessions. Hone’s wife appreciated the SLT’s persistence and the fact that the SLT “stuck with us through endurance” when “she could have given up long ago”. Even with on-going therapy, Hone had very limited expressive language ability. Despite this, he continued to be involved in his community. After the stroke his wife approached the kura kaupapa Māori (Māori immersion primary school) where he had been working and they welcomed him back in a voluntary capacity. His wife credited this voluntary job with keeping them both “sane”. Hone also retained his role on a local sports committee and as chairman of the marae trust board. His wife was concerned about his ability to fulfil his role on the trust board but his fellow trustees supported him, “I always say to him ‘you can’t talk so you shouldn’t really be the chair’ but the other trustees told me … ‘you don’t have to talk’”.

Because there was no community SLT service available in Hone’s area, his SLT was limited in the way she could help him and his community. Although Hone and his wife valued his therapy sessions, they were entirely separate to his community life, just something he did once a week by himself. Fortunately for Hone, his community recognised his skills and made use of them, despite his severe aphasia. They achieved this without the guidance of an SLT.

Part of the role of the SLT is to determine the best method of service delivery for the individual and their whānau at each point in time, within the confines of their workplace service delivery model. How well the SLT does this contributes to the therapeutic relationship. Makere enjoyed attending kaumātua (elders) group (this was initiated by her whānau not by the SLT). Latimer, Jack and Christine were all members of aphasia groups and enjoyed the whanaungatanga (relationship, sense of belonging) gained from attending. Margaret enjoyed singing in a choir for people with neurological conditions. Sam did not enjoy aphasia group but he was grateful for the whanaungatanga he experienced when the SLT arranged for him to have joint therapy sessions with an old friend of his, who also had aphasia.
Aphasia resources
Some participants described their SLTs providing therapy materials and tasks that they valued and enjoyed. Such resources usually demonstrated that the SLT recognised the interests and personalities of the person with aphasia and whānau. Christine was happy to work hard at traditional therapy exercises and she and her husband would go over and over the exercises in their own time. Sam appreciated the way his SLT based therapy sessions around playing card games. Jack was grateful that, along with the occupational therapist, his SLT encouraged him to play his clarinet again. Christine, Sam and Jack all reported having good relationships with their SLTs. It is likely that the use of appropriate resources contributed to these beneficial therapeutic relationships.

In contrast, the poor therapeutic relationship that Makere experienced was due in part to the use of inappropriate therapy resources. As was introduced earlier, Makere’s daughter recounted a situation in which Makere was given a reading passage that was totally unsuitable for her:

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 it wasn’t something that she was remotely interested in at all.

Shags are seabirds that frequent the coast and river in Tolaga Bay, the geographic centre of Makere’s tribal group, Te Aitanga-a-Hauiti. By using a resource that Makere was not interested in, the SLT was not acknowledging Makere’s identity through her ties to her family and land. This was detrimental to the therapeutic relationship and therefore to the success of therapy.

In addition to not being in te reo Māori and not being in keeping with their world view, Makere and her whānau also felt that the therapy resources did not reflect the “very capable woman” that she was. Makere’s son said that the SLT treated her as “the dumbest of the dumb”. He formed this opinion based on the resources used in therapy, which he called “primary school age ABCs type of thing”. He suggested that a more laid-back conversational approach would have been preferable, using everyday items like magazines and talking about relevant topics such as news and current events.

Is this as good as it gets?
This final theme forms the second part of the context for therapy. It encompasses the different quandaries that people with aphasia and whānau members found themselves in -
being concerned that they did not receive enough therapy, or the right therapy, and wondering whether it was worthwhile continuing with therapy. Margaret’s brother remembered her language therapy in hospital being “very erratic” – “My daughter spoke to a speech-language therapist at one stage and asked if there could be a regular monitoring of [Margaret’s] progress and… I think she was told that no, that wasn’t their modus operandi”. On a return visit to Sam during the research process he expressed disappointment that the SLT service to his town had just been terminated. He had been told that this was due to lack of funding. Most discussions about access to health services are centred on the public health system, but the problem can be wider than that. Makere’s family tried to engage the services of a private SLT for some additional input. Unfortunately they were unable to find one in their area.

During their interviews many families still wondered if there was more they could have done or could be doing to help with language rehabilitation. Hone’s wife spoke about how much work her sister had done with Hone while he was in hospital and how much progress he had made. She expected that Hone would have kept improving if her sister had been able to continue working with him – “I often think back and reflect and think ‘gosh if I had [sister] he’d have been talking by now’”. Makere’s whānau continued trying to do language exercises with her, although her daughter recognised that “we’re using stuff that we learnt eight years ago” because they had not had access to an SLT to get an updated programme. Makere’s son explained his on-going feeling that they should be doing more for Makere, even though her language was unlikely to improve:

> We’ve come to the understanding that Mum’s condition is not going to get better … and this is as good as it gets. So we live with “this is as good as it gets”...
> Communication-wise we could probably try repetitively doing the cue cards and flash cards and all those sort of things... we pull them out every now and again and have a go with them… we probably need to get better cards or more cards

At the time of Nan’s interview she was less than a year post-stroke and her daughters were wondering whether to accept the additional block of language therapy she had been offered. Nan had severe aphasia and apraxia. Her family reported that she had not received language therapy while she was in hospital. The reasons for this were unclear, but the family did not question it. When deciding whether to continue with outpatient therapy, Nan’s daughters recognised that therapy is hard work, particularly for an elderly person who is already unwell. They wanted to know how much Nan could expect to gain before deciding whether more therapy would be worthwhile. Like Nan’s family, Christine’s husband was starting to
question the purpose of Christine receiving more language therapy. Three years post onset of aphasia he was looking for a cure, and if language therapy could not offer a cure he did not want to pursue it.

**Discussion**

We have explored experiences of aphasia for Māori with aphasia and their whānau members, an area that has not previously been documented. This study will not only advance knowledge, but should inform practice (aligning with an ID approach) and ultimately improve quality of care and aphasia outcomes for Māori (thereby supporting the principles of KMR).

Māori with stroke have expressed the need for more SLT input during rehabilitation (Harwood, 2012) and Māori with disabilities have stated that they need to be proactive in order to receive services (Wiley, 2009). While some participants in the current study expressed disappointment with the amount or type of language therapy they received, others did not. At face value, the majority of participants were satisfied with the therapy they received. However, the critical approach of KMR calls us to look below the surface. The story about Hone returning to work is an example of this. His whānau did not tell this story as an example of inadequate SLT service. They told it to demonstrate who Hone is – his personality, identity, and achievements in spite of aphasia. It was only in the data analysis that the missed opportunity for SLT intervention became evident. Hone’s could have been a success story of SLT and whānau working together cross-culturally to facilitate a person with aphasia integrating into their community. However, it was not the SLT but whānau and community who helped Hone fulfil his community roles. Although the SLT cannot be involved in every aspect of a person’s life, and whānau members often take responsibility for rehabilitation, Hone might have achieved these outcomes faster or more easily if an SLT had been involved in the process. He was fortunate that his whānau and community were able to help him. Other Māori with aphasia will not have this advantage and will require more SLT assistance.

This study found that aphasia therapy for Māori relies on a few fundamental concepts – a collaborative process with whānau (“We’re happy to do the work, but we can’t do it alone”), a good therapeutic relationship, appreciating the world view of the person with aphasia and whānau, and the use of appropriate resources and therapy setting. Language rehabilitation for Māori with aphasia requires a collaborative approach. The SLT’s role, therefore, is to set
up the person with aphasia and whānau with education about aphasia and language therapy, provide appropriate therapy tasks, make sure the purpose of each task is understood, then provide guidance as required. Many whānau members will willingly put in hours of time and effort, as they are able.

In the current context, SLTs would be unwise to expect Māori with aphasia and whānau members to be forthright about their goals and expectations for therapy. Harwood (2012, p. 144) described the way Māori with stroke “stood their ground” against “systematic, interpersonal and internalised discrimination” but also recognised that “[m]aking a stand in the situation of clinical encounters is extremely difficult” (p.149). Similarly, Arlidge et al. (2009) identified that, in the unfamiliar hospital environment, Māori parents felt they were unable to be proactive in asking for help for their injured children. In the current study many participants with aphasia and whānau members were not familiar with what SLTs do for aphasia and how the rehabilitation process works. This reinforces the on-going need to increase public awareness of aphasia (McCann et al., 2013) and health literacy (Robson, 2002). Even Makere’s assertive, educated whānau described feeling largely powerless. Makere’s son demonstrated this as he reflected on whether his whānau should have insisted that their mother receive therapy in te reo Māori:

We probably could’ve spoken up, but if it’s your first time through a process you don’t know what the process involves until you’ve actually completed the process. And by then you can’t really go back and say “hey, let’s go back to step one and do it in Māori”

This narrative reflects not only a lack of cultural fit but also a lack of cultural safety. Cultural safety goes beyond “cultural appropriateness” to examine the power differential in relationships between health professionals and the people they serve (Ramsden, 2002).

The therapeutic relationship is of utmost importance for Māori with aphasia. Nan continued attending therapy because of a positive relationship with her therapists. In contrast, Makere tried to avoid therapy because of a negative relationship. This echoes the findings of Byng, Cairns, and Duchan (2002) and Hersh (2004, p. 102) who reported that “for clients, aphasia therapy and the personality and style of the aphasia therapist were deeply entwined”. Part of establishing a therapeutic relationship is using appropriate therapy materials. That is, because aphasia therapy and the SLT are entwined, the resources used in therapy demonstrate to the person with aphasia the therapist’s view of them. In Makere’s case we cannot know what the SLT actually thought about Makere’s ability. S/he had probably used
the “ducks in New York” passage with multiple different people with aphasia and never stopped to consider the appropriateness of it. However, what matters is the message that Makere and her family received. The resources that were used led Makere’s whānau to believe that the SLT thought she was “dumb”. For Jack and Sam, when the SLT tailored the therapy to their interests it showed them that she recognised their individual personalities and identities. The impact of using appropriate or inappropriate therapy materials has been illustrated by Hersh (2009) and Parr et al. (1997). Similar to the use of appropriate resources, an appropriate location and style of service delivery is also important. Armstrong et al. (2012) suggested that Aboriginal people with aphasia might benefit from aphasia education or language therapy being delivered through existing community groups, rather than a separate SLT service. The community involvement of many participants in the current study indicates that this might also be a fitting approach for some Māori with aphasia.

Further considerations

The data provided for this study have come from the clinicians themselves, based on self-reflection, clinical judgement and what they have learnt from working with Māori patients. They are therefore shaped by the individuals’ cultural awareness and ability to reflect on their practice and their colleagues’ practice. The SLTs who participated in this research were those who were interested in the topic and therefore likely to be the clinicians with the highest levels of “cultural desire”. It is possible that the SLTs who declined to participate, or those who did not show interest in the project, would have provided a very different perspective on service provision for Māori.

A strength of this study is the involvement of both SLT managers and clinicians. Managers offered insight from a systems, funding and staffing perspective, as well as speaking about their own clinical work, while SLTs spoke about working clinically within these systems. There were difficulties inherent in interviewing SLT managers. One manager expressed concern that her contribution was unlikely to be truly anonymous because of the small number of people in positions like hers. She said that, while she wanted to be candid in her comments, she was concerned that, in being so, she, and therefore her staff, might be identifiable. While we assured participants that we would do everything possible to protect their identities and encouraged them to edit their transcripts before analysis began, there is the possibility that they were less than candid because of the small size of the profession and a perceived difficulty preserving anonymity.
Although equal explanatory power is a quantitative concept, and this is a qualitative study, the principles are valid in this study. Equal explanatory power means “producing information for Māori health development to at least the same depth and breadth as that obtained for non-Māori health development” (Robson, 2002, p. 2). This includes making sure that health surveys involve sufficient numbers of Māori and non-Māori to enable robust statistical analysis that can be used to explain and address disparities (Robson, 2002). In this qualitative study, although the participant sample reflects the proportions of the SLT population, and the contributions of the individual participants are not necessarily equally-weighted, the one Māori voice in the group tended to be drowned out by the non-Māori majority. However, with only 15 Māori SLTs as full or provisional NZSTA members (NZSTA, personal communication, 2013), not all of them working with people with aphasia, and one being the researcher, it was not possible to recruit any more Māori participants. The research could be improved by identifying ways to increase the breadth and depth of the Māori voice in the cohort without increasing the number of Māori participants.

**Further considerations**

A strength of this study is the combined use of KMR and ID. The use of an applied qualitative methodology within a Māori research approach facilitated a study that tells the stories of Māori with aphasia and their whānau members while enabling SLTs to learn from them. The findings are clinically applicable and relevant both to Māori communities and clinicians. The critical approach of KMR revealed problems that were not overt, while the disciplinary grounding of ID ensured that practical learning for SLTs can be taken from the situation. Another strength is that people with aphasia and family members were interviewed together. This allowed different perspectives to be given as whānau told their story as a group.

A limitation of this study is that most participants were recruited via their SLTs. Therefore, they were aware that the interviewer knew their SLT. Even though participants were assured of confidentiality, they might have withheld negative experiences for fear of their SLT finding out. Similarly, participants were aware that the interviewer was an SLT and may have not have wanted to cause offence. However, participants appeared to be candid in their comments, as one said, “I think they were a bunch of losers these therapists, not saying that you are, but the ones that we encountered”.
The focus of this study was on the experiences of Māori with aphasia and their whānau. The experience of language therapy is one part of that (although for most whānau it was only a small part). Therefore, this article consists of interpreted descriptions of participants’ experiences, both good and bad. Because there is no existing literature about Māori experiences of aphasia or SLT, it was necessary to lay the foundation for future research by describing and interpreting the current situation. The kuia who provided guidance for this project recognised that the findings are likely to benefit all people with aphasia and she asked that the participants’ stories contribute to the “bigger picture” that is aphasia research.

This article has addressed aphasia therapy from the perspective of Māori with aphasia and whānau members. The picture is not complete without also considering the perspectives of SLTs. Future research will incorporate the findings of this study, and the wider study from which they came, with analysis of the experiences of SLTs who provide therapy for Māori with aphasia. With a focus on clinical application, more targeted questions and discussion points can then be developed and used to inform solutions-focused research involving Māori with aphasia, whānau members and SLTs, to benefit the wider aphasia community.

**Conclusion**

The findings of this study show that, while some Māori with aphasia receive a service that is accessible and respectful of their culture, others do not. Many receive a service that is somewhere in between – it is not inaccessible or disrespectful, but it could be greatly enhanced with attention to a few fundamental concepts. Successful therapy for Māori with aphasia stems from a mutually respectful therapeutic relationship. It is a collaborative process in which whānau are supported to undertake their rehabilitation in a style that suits them, using resources that affirm their identity.

**References**


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Chapter 6: New Zealand speech-language therapists’ perspectives on service provision for Māori with aphasia


This publication is inserted as it will be submitted for publication, with the exception of minor edits and formatting changes to maintain consistency throughout the thesis.
Abstract

This article examines the experiences of SLTs who provide services for Māori with aphasia.

The *New Zealand Disability Strategy* states that disability services should be “accessible to and culturally appropriate for disabled Māori and their whānau” (Minister for Disability Issues, 2001, p. 25). However, with no published literature about the experiences of Māori with aphasia and their whānau, SLTs have little guidance as to what makes a service “accessible” and “culturally appropriate”.

In light of this, this study sought to describe and analyse current service provision for Māori with aphasia and SLTs’ concepts of an accessible and culturally appropriate service. Using the qualitative methodology of interpretive description, interviews were conducted with 10 SLTs (five managers and five clinicians) working with Māori with aphasia across New Zealand. Inductive analysis revealed three factors that together determine the service provided for Māori with aphasia. These are “SLT factors”, “Ways of working” and “Resources” (human and non-human). “SLT factors” are specific to the individual clinician and include their knowledge, attitudes and willingness to make connections. “Ways of working” include team culture and expectations as well as such practical aspects as the timing and location of SLT appointments and the content of the sessions. “Resources” include the people, funding, assessments and therapy materials that are available. As each of these factors varies greatly between districts, the service provided for Māori with aphasia varies as well. The results show that, although there are many limitations to their practice, SLTs desire to provide an accessible, culturally safe and culturally appropriate service for Māori with aphasia.
Taking the perspective of SLTs, this article examines the clinician and service delivery factors thought to impact on the experiences of Māori with aphasia. The NZDS (Minister for Disability Issues, 2001) and HKO (Minister of Health and Associate Minister of Health, 2002) give generic recommendations for health and disability service providers which suggest that there is a role for the SLT in working with Māori with aphasia. In accordance with Objective 11 of the NZDS (“Promote participation of disabled Māori”), SLTs have a responsibility to ensure their service is “accessible to and culturally appropriate for disabled Māori and their whānau” (Minister for Disability Issues, 2001, p. 25). “Disabled Māori” includes Māori with aphasia. An SLT working in line with HKO would take a holistic approach to health and wellness as s/he supported Māori with aphasia and whānau members to live with aphasia. The SLT would work in partnership with Māori communities to improve services and outcomes for Māori with aphasia. Māori would be involved in service planning and delivery. Māori cultural values would be protected and Māori with aphasia would enjoy the same standard of rehabilitation outcomes as non-Māori. The SLT would recognise that “health and wellbeing are influenced by the ‘collective’ as well as the individual, and the importance of working with people in their social contexts” (Minister of Health and Associate Minister of Health, 2002, p. 1). An approach such as this is likely to be a new way of working for many SLTs, although, with no record of current SLT service provision for Māori, one cannot know for sure.

With no published literature about the experiences of Māori with aphasia and their whānau (McLellan et al., 2011), SLTs have little guidance as to current or ideal service delivery for this population. This problem is not specific to New Zealand, having recently been identified for Indigenous peoples in Australia as well (Rose, Ferguson, Power, Togher, & Worrall, 2013, p. 10). In New Zealand, Wiley (2009) conducted an outcome evaluation of Objective 11 of the NZDS, in which she interviewed, among others, service providers and service-users with disabilities. While the majority of service providers reported that their service accessibility for Māori was “good” or higher, Māori with disabilities reported many dissatisfying aspects, including the fact that service providers did not acknowledge their cultural needs. Wiley’s (2009) evaluation of the NZDS suggests that there is a risk that current SLT service provision might not be meeting the objectives of the NZDS and HKO.

Most SLT services for Māori with aphasia are delivered by non-Māori SLTs. The exact number of Māori SLTs working with adults with aphasia is unknown. Approximately 2.5-3% of all SLTs in New Zealand are Māori (personal communication, NZSTA: Allied Health
Workforce Strategy Group, 2007). Although each clinician’s professional identity is largely determined by their own culture, it is influenced by the culture of their profession (in this case SLT), their gender, and the health care system in which they work (Kagawa-Singer & Kassim-Lakha, 2003). This means that SLT encounters will always be cross-cultural, even if the patient and clinician are from the same cultural background. The cross-cultural differences are likely to be accentuated when the clinician and patient are from different cultural backgrounds.

In New Zealand’s health system, the majority of health care received by Māori is cross-cultural. Therefore SLTs need to be culturally safe and culturally competent. Focusing on nursing, but also relevant to SLT, Ramsden (2000, p. 10) wrote that cultural safety “lies in the establishment of the trust moment and in shared meaning about vulnerability and power followed by the careful negotiation of the legitimacy of difference”. Campinha-Bacote (2002, p. 181) stated that cultural competence is “an essential component in rendering effective and culturally responsive services”. The NZSTA Programme Accreditation Committee has recognised the importance of cultural competency and drafted a set of “Cultural Competency Measures for Entry Level Students” (NZSTA, personal communication, 2013) as a way of determining the cultural competence of SLT graduates. However, the majority of the SLT literature about working with “culturally and linguistically diverse” clients, focuses on linguistic aspects of aphasia in bilingual “minorities” (not necessarily Indigenous peoples) (e.g. Centeno, 2009; D’Souza et al., 2012). These studies emphasise the limitations when SLTs are unable to provide therapy for patients in their chosen language. They make only passing reference to the culture of the person with aphasia and do not mention the cultural competence of the SLT. Roger (1998, p. 137) recognised the importance of culture when he argued for “an approach which integrates the social, cultural and linguistic dimensions of bilingual aphasia” but he did not specifically mention the cultural competence of the SLT.

Clinicians’ attitudes towards their patients are known to be influenced by cultural and ethnic differences (Rathore et al., 2000; van Ryn & Burke, 2000). When clinician and patient are of a different ethnicity, biases include the clinician feeling a lower affinity with the patient (van Ryn & Burke, 2000), and difficulty developing a positive therapeutic relationship (Qureshi & Collazos, 2011). In addition, the clinician has been shown to have a role in the current inequalities in health outcomes for Māori, including, for example, ischaemic heart disease (Curtis et al., 2010). Although these studies involved medical students (Rathore et
al., 2000), physicians (Curtis et al., 2010; van Ryn & Burke, 2000), and mental health professionals (Qureshi & Collazos, 2011), not SLTs, the findings are likely to be applicable to SLTs as well. Difficulty with the therapeutic relationship is of particular concern because the therapeutic relationship is very important in aphasia therapy (Fourie, 2009; Hersh, 2004; Parr et al., 1997; Worrall et al., 2010). Because of egalitarian beliefs, clinicians are often unaware of their biases (Burgess, Fu, & Van Ryn, 2004) and can find it difficult to accept that they contribute to health inequities (Van Ryn & Fu, 2003).

In summary, SLTs are compelled to follow the NZDS and HKO but there is little guidance on how to ensure that a service that is accessible to and culturally appropriate for Māori. In addition, there is no record of the service SLTs are currently providing for Māori with aphasia. Therefore, in this study we aimed to describe SLTs’ perceptions of factors affecting their current service provision for Māori with aphasia, and their concept of an accessible and culturally appropriate service. An additional aim was to gauge whether SLTs report that Māori with aphasia are underrepresented on SLTs’ caseloads, as has previously been observed (McLellan et al., 2011).

**Methodology**

This study used the qualitative methodology ID (Thorne, 2008). ID is “a disciplinary approach to qualitative research” (Thorne, 2008, p. 73) that originated in nursing. ID studies focus on producing relevant and clinically applicable findings. As an inductive methodology, the analysis develops from the data rather than proving or disproving an existing theory. The inductive approach was important for the current study because there was no existing data or theory about service provision for Māori with aphasia. ID is grounded in a discipline (in this case, SLT). ID researchers acknowledge the influence that their disciplinary knowledge will have on the research and attempt to minimise its unintended impact, but do not bracket it or set it aside (Thorne, 2008). Because this study was part of a larger KMR study, it was also shaped and influenced by the principles of KMR detailed in Chapter 3. We took a critical approach towards data analysis to ensure the research was decolonising (Pihama, 2011). In addition, the research was transformative (Pihama, 2011), aiming to make a practical difference for Māori with aphasia.

**Procedure**

Approval was granted by the University of Auckland Human Participants Ethics Committee.
**Participants**
This study involved 10 SLTs from across New Zealand. ID does not dictate a sample size. Thorne (2008) notes that most ID studies are likely to have between five and 30 participants and suggests that “smaller interpretive description studies are justified in having set somewhat arbitrary sample limits, as long as they show recognition that there would always be more to study” (p. 98). All participants were approached by the researcher and invited to participate. They had previously expressed interest in the research by recommending participants for a larger study investigating the experiences of Māori with aphasia or by approaching the researcher to discuss the topic. A total of 15 SLTs were approached but five declined to participate or did not respond to emails.

All participants were working, or had recently worked, for a DHB across New Zealand. Five participants were working, or had worked, as SLT managers (with or without control of budgets) and five were clinicians. Purposive sampling was used (Thorne, 2008), based on the following factors which are known or expected to influence service delivery for Māori:

- Ethnicity. Clinicians’ attitudes towards their patients are influenced by cultural and ethnic differences between clinician and patient (Rathore et al., 2000; van Ryn & Burke, 2000)
- Trained in New Zealand versus overseas. New Zealand SLT training programmes are required to provide training in cultural competence and the Treaty of Waitangi (New Zealand Speech-language Therapists’ Association, 2011)
- Years of work experience in NZ. SLTs with more work experience in New Zealand are likely to have spent more time working with Māori whānau and had more opportunities for cultural competence training in the workplace, but fewer opportunities for cultural competence training in their university courses. The content of the NZSTA “Accreditation standard for the New Zealand Context” increased greatly between the 2001 framework (New Zealand Speech-language Therapists’ Association Incorporated, 2002) and the 2011 revised framework (New Zealand Speech-language Therapists’ Association, 2011). Before 2002 there was no programme accreditation framework (personal communication, Jo de Seriere 2013)
- Years of work experience overseas. SLTs are likely to be influenced by the attitudes of the countries in which they have worked
• Demographics of the population that their workplace serves. Service provision is likely to be influenced by the number of Māori patients in their area and whether it is a rural or urban area
• Type of service the workplace provides (inpatient/outpatient/community). Style of service delivery determines the ways in which SLTs are able to work with Māori patients

All participants were female. Six identified as New Zealand European, one New Zealand Māori (who also identified as New Zealand European and Other European) and three Other European. Seven had trained in New Zealand, three overseas. Total years of SLT experience ranged from four to 30 (mean 14 years). Years of New Zealand experience ranged from four to 20 (mean 9.7). Seven participants had some overseas work experience (mean length six years). This was mainly in the United Kingdom and Ireland, with some experience in Australia and some volunteering in third world countries. Participants provided services for a mixture of inpatients, outpatients and community in rural and urban areas (some purely urban, some purely rural, some both) and all had worked with Māori with aphasia.

Ideally this sample would be representative of the SLTs working with Māori with aphasia in New Zealand. However, because SLT is not a registered profession, demographic information about the workforce is not available. We therefore obtained demographic information from the NZSTA, the professional body for SLTs in New Zealand. It is estimated that half of all SLTs are NZSTA members (NZSTA, personal communication, 2013). In 2012, NZSTA membership was almost entirely female, 30% trained overseas and 2.6% identified as Māori (NZSTA, personal communication, 2013). The current cohort has similar proportions to the NZSTA membership, being all female, 30% trained overseas, and 10% Māori. With a mean 14 years work experience, this group is likely to be more experienced than the average NZSTA membership.

Data collection
Data were collected during one interview with each participant. All interviews were undertaken by the researcher. Where possible, interviews were conducted face-to-face in a location of the participant’s choosing. Four were interviewed at their workplace, one at home, and two at the university. Due to distance, one was interviewed via telephone and two via Skype. After speaking about their experiences of providing or managing SLT services for Māori with aphasia, participants were asked to describe what an accessible and culturally appropriate service would look like, and barriers and facilitators to making a
service accessible and culturally appropriate. In addition, participants were asked to comment on the number of Māori with aphasia they or their service worked with. SLTs were not asked to explain how they identified that a person with aphasia was Māori. It is presumed that they had access to the ethnicity data gathered by the DHB, and any other information gained in conversation with the person and whānau. The main focus of the interviews was the SLT’s experiences and learnings over the course of their career. The average duration of the interviews was 30 minutes.

Data analysis
All interviews were recorded and transcribed. Inductive analysis started with reading and re-reading the transcripts. Following that, transcripts were coded using NVivo 10 software. Three factors that determine the service provided for Māori emerged. Each of these was made up of several contributing factors. Memos were written throughout analysis to document the developing findings and analysis was discussed with other members of the research team. In ID the researcher is advised to present participants with the early analysis and seek their comment about whether the findings represent their experiences. Therefore, participants were emailed a diagram and written summary of the developing findings and invited to contact the researcher to discuss the findings or offer comments. The four participants who responded were positive but highlighted areas that they thought had not been addressed sufficiently in the analysis. Reporting of the findings was modified to ensure the identified areas received sufficient emphasis.

Rigour
The “evaluative criteria” for rigour in ID are epistemological integrity, representative credibility, analytic logic and interpretive authority (Thorne, 2008, pp. 223-225). Epistemological integrity means that there should be a logical connection between the stated epistemology (theory of knowledge) and the research question that is asked. In addition, the interpretation of data must be in keeping with the research question. “[I]nterpretive description explicitly locates itself within the applied disciplinary domain” (Thorne, 2008, p. 68). Therefore, in order for research to have epistemological integrity, it must be clear that the research topic, approach, and data analysis have been formed by the theory, knowledge and practice of the discipline (in this case, SLT). Furthermore, these are not used to create further disciplinary theory but to address applied clinical questions (Thorne, 2008). Accordingly, this research addressed SLTs’ perspectives on service delivery for Māori with aphasia. While the findings of this study might further disciplinary theory to a small extent,
their focus is on “describing” and interpreting patterns of experience, action, or expression” (Thorne, 2008, p. 68) to inform and enhance SLT practice. The influences of the theory, knowledge, and practice of SLT are acknowledged.

Studies demonstrate representative credibility when the findings are consistent with the population sampled. That is, not claiming to represent anything beyond the characteristics of the participant group. We recognise that the participants in this study are those who gave their time to talk about service provision for Māori. These are probably people who feel strongly about the topic. The findings are only representative of the views of this group of participants and it is possible that they present a more positive view than that of the New Zealand SLT workforce as a whole.

Analytic logic requires the researcher to demonstrate logical reasoning that moves from raw data to interpreted findings. This was achieved by creating an audit trail. Memoing was completed after each interview and regularly during the analysis process. Quotes from participants are provided throughout this article to illustrate how themes were obtained.

Interpretive authority means that the findings go beyond the researcher’s own subjective experience to reveal common truths. As a Māori SLT, the researcher brought a discipline-specific and culture-specific view to the analysis. The first step towards interpretive authority was recognising this fact and the impact it could have on the interpretation of the data. Interpretive authority was ensured by discussing the developing findings with the research team, which included non-Māori SLTs and a Māori non-SLT.

**Results**

This section begins with participants’ comments on the number of Māori with aphasia on their caseloads and a discussion of those findings. That is followed by a parallel description of current service provision for Māori with aphasia and SLTs’ concepts of what makes a service accessible and culturally appropriate.

**Māori with aphasia on SLT caseloads**

The number of Māori with aphasia each clinician had on her caseload varied greatly, although exact numbers were not sought. One SLT reported working with large numbers of Māori with aphasia. She worked in an area with a Māori population higher than the national average and was able to be very flexible in service provision. Another SLT noted that in a previous job she had seen a lot of Māori with aphasia as inpatients, outpatients, and in the
community. In contrast, in her current position she saw Māori patients in the hospital but very few after they were discharged home. She thought this might be because they only offered outpatient appointments, not home visits, and explained “Quite often they live quite a long way away and it’s too hard for them to get into the hospital. It’s expensive with transport and parking, it’s just not really a viable option”.

Many participants reported having small numbers of Māori with aphasia on their caseloads. They did not know for sure why the numbers were small, but suggested a variety of possible reasons. One SLT observed that, “We don’t have a lot of Māori people coming through… It’s surprising because we have quite a high percentage of Māori people that live in this area”. She wondered if the small number of Māori on her caseload could be due to “the luck of the draw” or linked to “how they access health services”. She also considered that Māori with aphasia might be sitting on the language therapy waiting lists that were a problem in the rural outposts (which have a higher Māori population).

A manager in a different area remembered seeing only three or four Māori with aphasia over a three year period. She wondered if that was reflective of the small Māori population in her area, or because she worked in an urban area and Māori with aphasia might have received rehabilitation in smaller rural centres closer to their homes. An SLT in a nearby area commented “I could count on one hand how many Māori I’ve seen in [city] with aphasia. I don’t know where they go or what happens”. She suggested that it might be related to age – she worked with people over 65 years and wondered if most Māori with stroke were younger.

There are many factors influencing the number of Māori with aphasia on SLT caseloads. The SLT was correct when she observed that Māori have a younger age for stroke onset and therefore were not on her caseload of people over 65. In the years 2002-2003 the mean age of stroke onset for Māori was 60.7 years, almost 15 years younger than the average for Europeans, which was 75.6 years (Carter et al., 2006). This is a concern because, in New Zealand, people aged under 65 have less access to rehabilitation services than those over 65 (Fink, 2006). The percentage of the population that is Māori varies across New Zealand. This will have some impact on the number of Māori being seen by SLTs in each district. However, given that Māori aged 35 years and over are hospitalised with stroke at twice the rate of non-Māori (Ministry of Health, 2010), a reasonable number of Māori with aphasia is to be expected, even in areas with a relatively small Māori population. This, coupled with
SLTs’ observations detailed above, suggests that in many areas of New Zealand Māori are under-represented on SLT caseloads.

**Factors that determine the service provided for Māori with aphasia**

Analysis revealed three factors that together determine the service provided for Māori with aphasia. These are “SLT factors”, “Ways of working” and “Resources” (human and non-human). These factors, and the contributing factors that constitute them, are detailed in table 4. We will address each of the factors in turn and then demonstrate how they come together to influence the service.

**Table 4 Factors that determine service provision for Māori**

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<td>SLT Factors</td>
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<td>Non-human resources:</td>
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<td></td>
<td>Funding and evidence base</td>
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<td>“We’re just too busy”</td>
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<td>Resources for use in therapy</td>
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**SLT factors**

SLT factors are the individuals’ learning, knowledge (or inadequacy of knowledge), attitudes and willingness to make connections that contribute to their cultural competence and the service they provide. When considering these SLT factors, the only available data are those which have come from the clinicians themselves. They are, therefore, shaped by the individuals’ perspectives and ability to reflect on their practice and their colleagues’ practice.
Some participants were strongly aware of their lack of knowledge when working with Māori with aphasia. One manager described her situation “The more you know, the more you know you don’t know. So it’s forever an on-going cycle of inadequacy of knowledge”. Others did not demonstrate this level of insight but identified specific gaps in their own knowledge, such as an inability to speak te reo Māori.

At the other end of the awareness scale, one manager spoke of the need to challenge her SLT staff about “the services that they provide, the assumptions that they make” and her concern that the “person that doesn’t know what they’re doing, that doesn’t understand some of the issues, won’t be the one that will bring it up”. This manager had observed that staff who are not aware of their ignorance will “think that they know, and not only that they know, but that they practise appropriately, when in fact that’s not happening”. This situation is further complicated by the manager, who described herself as having “a reasonably shallow level of understanding of tikanga Māori”, not being fully confident in her own knowledge. Other managers also acknowledged the difficulty in enabling staff to work in a culturally safe way when they were not “super confident” themselves.

There were a few examples of the belief that one was practising in a culturally safe manner if they applied what they had learnt about cultural practices. For example:

I still try to remember the things that they taught us in Treaty of Waitangi [course] about you not touching their face or head without asking permission and you take your shoes off before you go into anyone’s house… but overall I try to just be myself.

In contrast, another clinician acknowledged the depth of understanding that is required when she said “I guess that you sort of feel quite aware sometimes that you have a responsibility to provide a culturally appropriate service but sometimes it can be hard to know how exactly to go about that”. And one stated “we can’t assume that the one size fits all and that, what we think is often best practice and culturally safe and culturally competent practice, actually it might not be”.

Participants commonly stated that “not every Māori sees culture the same way”. This belief made some clinicians reluctant to describe best practice for Māori:

I think if I can sum it all up I’d say everyone’s an individual and I have to treat everyone on an individual basis. I have to take culture into consideration, but I can’t build assumptions based on it
While aiming to treat all patients as individuals, the place of Māori as tangata whenua was not always recognised, for example “we would try and use culturally appropriate materials, but we would do that with any culture”.

Belief in the need to treat each person as an individual, coupled with an awareness of their own lack of knowledge, could have a paralysing effect on clinicians when working with Māori. One manager had noticed that staff were “well-intentioned, but they were so worried about getting it wrong that they wouldn’t even try”.

Two participants demonstrated insight into their cultural competence but did not mention inadequacies in their knowledge or experience. Compared to the other participants, these two SLTs appeared to have the most involvement in the Māori world. One said of her work “It hasn’t been a sort of a big deal... The people that I work with, some are Māori and some are Pākehā”. The other referred to having lots of experience with Māori with aphasia, but could remember few specific cases. It appeared that, for these SLTs, Māori patients were not particularly memorable, just normal. When asked to identify barriers to their service provision for Māori, one of these SLTs identified the main barriers as the small number of Māori SLTs and a lack of cultural competence in the SLT workforce. The other identified a lack of coffee-making facilities in her workplace:

Interviewer:

Are there any barriers within the systems that you have to work with… or anything that’s a barrier for you in providing a service for Māori?

SLT:

… I often find myself making cups of tea and coffee… often if [patients] have had to travel a distance. And we don’t actually have facilities for that… I’d actually like a room that had coffee-making facilities… just to give something to make them feel at home, and to acknowledge that they’ve come a distance.

In the context of the whole interview, this response demonstrates two things. The fact that the SLT recognises the need for coffee-making facilities shows that she practises the Māori value of manaakitanga (hospitality). The fact that she identified the lack of coffee-making facilities as the main systemic barrier demonstrates that she is able to work in a culturally safe way for all other aspects of her work.
Regardless of their knowledge or their perception of their knowledge, almost all participants spoke about the need to make a connection with Māori with aphasia and whānau members. Some clinicians acknowledged difficulties with making connections:

There’s us the professionals who come from this world and then there’s the Māori patients and family and so on, and there’s kind of two separate worlds there. And while we’re certainly doing our best to help them… there’s us and there’s them and I’m not sure that there’s that good a meeting of the two

Many participants were aware of the limitation of being a non-Māori clinician working with Māori. One SLT referred to herself as “an outsider” and another said “at times I felt like I come from a different world and I don’t quite know how to bridge that gap”. Most acknowledged their situation and managed it unapologetically – “I don’t make excuses for myself”. Participants recognised that their personal identity was important in making connections with Māori whānau. One therapist was learning te reo Māori. Another made a “pictorial mihi” (greeting) so that she could introduce herself and connect without relying on spoken language. An overseas-trained clinician discovered that her connection to her home country helped her to connect with Māori families. This was because many Māori had genealogical links to her country, and both countries had experienced colonisation. Because relationships vary and people connect in different ways, one manager suggested that for aphasia therapy for Māori whānau:

It would be great if it was an inter-professional service and you would have maybe the key person going out who would actually be the one who has the best engagement with that particular family… it might be different people at different times.

Ways of working

The ways of working in an SLT team and the wider service-provider have a large influence on service delivery for Māori with aphasia. They simultaneously determine how an individual clinician can work and are determined by the knowledge and attitudes of the collective. Ways of working include those related to team culture, such as the expectations placed on clinicians, the flexibility of systems, the PD that is available and the commitment to whānau-centred care. They also include more practical aspects such as the timing of SLT input, location of appointments and the language and content of therapy sessions.

Team culture

Participants agreed that team culture has a profound influence on service delivery for Māori with aphasia. As such, experiences varied greatly between participants. Managers spoke
about creating a team culture in which reflective practice was expected, and acknowledged that “working in a culturally safe way isn’t just something you do as a one-off; it’s something you need to constantly be reflecting on”. The impact of team culture was salient for one clinician who perceived that her previous team had a greater focus on service provision for Māori than her current team. She described her current practice being limited by “having a workplace culture that’s not strongly focused on looking at culturally accessible services for Māori” and noted that “a culture and management that promote and prioritise that sort of thing makes a huge difference”. Some managers spoke about the requirement for staff to show “Māori responsiveness” in their performance appraisals. However, this was not evident in all workplaces, as one clinician said, “We’re all supposed to be culturally appropriate… especially politically, everyone places such importance on culture that the fact that it’s not compulsory to keep up-skilling yourself or keep reminding yourself about it is a bit remiss”. Managers acknowledged that it was difficult to measure and evaluate cultural safety within a team, and the cultural-appropriateness of interventions. One manager had started using Te Whare Tapa Whā as a way of measuring outcomes:

So where something like AusTOMs [Australian Therapy Outcome Measures] will look at your outcome, you could measure your SLT performance against a Te Whare Tapa Whā model and say “actually did I provide within my session just a physical focus or was there something else going on there that was truly honouring to that model of wellness and health?”… I think it’s a sound way of measuring outcomes… it has a lot of culturally safe challenges… but it’s a start

With statements such as “it is changing”, “the momentum just needs to keep going” and “the thing I like about New Zealand is that you can actually use a bit of initiative and get stuff done”, participants acknowledged that they could influence the culture of their workplace to some extent to influence the service provided for Māori. However, they faced many limitations due to inflexible medical-model-based systems. One manager explained, “We’ve got a system and a bureaucracy in terms of healthcare that’s quite prescribed and not known for its flexibility”. Another manager emphasised how difficult it is to work in a culturally safe way within such a system, “If you’re not feeling particularly strong in your own identity as a clinician you can get swayed into those medical models quite easily”. While most participants spoke about systems being inflexible, some acknowledged the human component. A manager pointed out that “people create systems” and a clinician...
observed “I’m not sure the people that could make the changes are interested in making the changes”.

While participants generally acknowledged that a change in service provision for Māori with aphasia is required, one manager questioned whether the profession of SLT is ready to make that change, “I don’t know that… we’re ready or able yet to change our model – our service delivery model as well as our scope of practice models – and feel comfortable with that”.

**Professional and personal development**
Wider workplace culture and the expectations of management determined the PD that was available to clinicians and managers. As a result, experiences of PD varied greatly between participants. A manager talked about allocating funds for staff to attend an optional “extended” Treaty of Waitangi course, which she called “really important”. Two other participants spoke highly of the “tikanga” courses provided by their employers. In contrast, an overseas-trained clinician described the negative effect of her workplace Treaty of Waitangi course, which was her first introduction to Māori culture:

> They told us a lot about how to work in a culturally sensitive way, but also there was a little bit of “oh you people have come here and because of you our family members don’t have any of their afterbirths” and we actually got told some really extreme things. So finally when I went to see my first Māori client I was really intimidated and really scared because of the Treaty of Waitangi course.

As well as this unhelpful content within PD sessions, participants described having limited time for PD and a lack of managerial support. One SLT, who admitted that after five years in the job she still had not done the compulsory Treaty of Waitangi course, spoke about cultural safety training not being a focus in her workplace:

> We’ve got all these criteria, you have to have health and safety training, you have to have your first aid, and you have to have your manual handling. And there really should be you have to have either a takawaenga in-service or some kind of cultural, you know, tick box.

Several participants had derived benefit from a series of teleconferences about the Treaty of Waitangi and SLT practice in New Zealand that had recently been provided by the NZSTA. While she acknowledged how beneficial the teleconferences had been, one manager thought that the NZSTA should have provided that training many years earlier and there should be annual updates.
Separate to formal PD, participants benefited from personal experiences in Māori environments. One clinician described the relationship a Māori colleague had developed with her and her family when they first arrived from overseas. They were invited to the colleague’s marae for pōwhiri, wānanga, tangi and other whānau events. The SLT reflected “I think having that insight has probably helped me hugely in my work”.

**Whānau-centred care**
Participants recognised that, for Māori with aphasia, whānau-centred care was important. True whānau-centred care requires a lot of time spent building relationship and collaboratively setting goals, as this manager explained, “You can’t just jump straight in. You actually need to take the time to gather the information and work out what’s important to this person and get them on board and engage with them yourself”. Therefore, one’s ability to carry it out will be influenced by his/her team’s way of working.

While recognising the need for whānau-centred care, clinicians acknowledged many challenges. Sometimes challenges came with cross-cultural service delivery:

> There’s often a very extended whānau who are all present and there’s quite often been occasions where I’ve walked into a room and there’s people everywhere, all sort of looking at you and you don’t know quite who to address yourself to or what to say

Difficulties were not only related to cross-cultural engagement with whānau. A Māori clinician said “I actually found it quite hard to get Māori whānau on board even though, being Māori myself. Just in terms of their working life or getting them to come in to those [hospital] settings”.

**Timing of therapy and the therapy setting**
Participants recognised the need for language therapy to be available when the person with aphasia was ready for it, and the limitations they faced in this regard. For some services inflexible systems meant aphasia therapy was only available in hospital and immediately after discharge, whether the patient was ready for it or not:

> I’d love a service where you could say “actually this person just needs to be at home now with their family, safe, and we need to be getting involved a couple of months down the track”. Whereas unfortunately there’s not that flexibility in the health service

An equal but different problem was long waiting lists:
The longer the waiting lists are, I guess the more attrition we have. Not just from death, but from [patients] not being so aware of us anymore, maybe not wanting us anymore. Maybe they don’t feel important enough to us anymore.

The location and facilities available for service delivery varied greatly between workplaces. One therapist worked for a rehabilitation service that, over 10 years earlier, had changed its service delivery to better suit Māori clients:

They acknowledged that Māori weren’t being seen, weren’t getting services, and it was mainly because it didn’t seem to be appropriate for them to come as outpatients. So they set up a service where we could go into their homes. That works a lot better.

Most, but not all, therapists were able to visit people in their homes and communities. There was a wide variation in how flexible clinicians could be with appointment times. The SLTs quoted below work in separate hospitals that serve different large rural regions with high Māori populations. The contrast in the service they were able to provide was stark. One service was very flexible – “I would make my initial visit in their home and then, because [town] is the main shopping centre, I’d say ‘well when’s your shopping day? Does it work for you to come [to the clinic that day]?’” In contrast, the other service had no flexibility:

They have to come in on a [specific] afternoon because that’s when my clinic is, and the only slot is [at a specific time] and they have to get into the hospital and they live in [town over an hour away]. I mean, it’s just impossible.

While most therapists found home visits beneficial, some acknowledged that home visits might be a barrier for some Māori with aphasia. One SLT relayed what her client had told her, “She said ‘I just felt invaded. My home is my nest and I had all these people coming in. Just constantly coming in and invading my special place’”. A rural SLT suggested that “for people that feel a bit shy about… people coming to their home” she could offer to meet people in one of the many community centres around her region, “a place that’s friendly”.

This therapist knew of a local family doctor who was running a successful drop-in clinic. She wondered about following a similar model for language therapy, since her employer afforded her the flexibility to structure her service delivery to suit her patients.

Language medium for therapy delivery
When thinking about the language and content of aphasia therapy, participants recognised that “ideally [therapy] should be in the language of the choice for that patient”. However, they described very few occasions when they had been asked to provide therapy in te reo Māori. One SLT explained:
In the initial assessment I’ll speak to them about using te reo and whether they want to work on that as part of therapy. And it’s kind of surprised me because loads of people have said to me “oh no, that’s not important, what’s important is my English and I really want to focus on that”

One manager suspected that the language in which therapy was delivered was influenced more by the attitude of the clinician than the preference of the person with aphasia, “There aren’t very many te reo Māori-only speakers. They usually can speak English so we assume that that’s the language that they want, or because we can that’s how we’ll treat them”

When approaching therapy for Māori with aphasia, clinicians thought that social approaches to therapy fit well with Māori models of health such as Te Whare Tapa Whā. They spoke about making sure that assessment and therapy were functional and focused on “re-establish[ing] their cultural identity”.

**Resources**
Service provision for Māori with aphasia is greatly influenced by resources, both human resources and non-human resources.

**Human resources**
Participants acknowledged that services for Māori with aphasia would benefit from the workforce having more Māori SLTs. Most, but not all, thought that Māori patients would be better served by Māori therapists. All agreed that it would be helpful to have Māori SLT colleagues, to provide cultural advice from an SLT perspective, even if they did not specifically work with the Māori patients. Participants also acknowledged the need for SLTs (Māori or non-Māori) who speak te reo Māori and are able to conduct therapy in that language.

Clinicians and managers expressed a desire to foster stronger relationships with Māori colleagues and communities. Some acknowledged that planning for a service to be accessible and culturally appropriate for Māori with aphasia should be done in partnership with Māori, even though “that might mean, therefore, SLTs needing to give up a bit of what we think is our role”. Participants valued the guidance provided by Māori colleagues (non-SLT), whom some called “the bridge” between clinicians and Māori with aphasia. The majority were specifically employed as Māori support workers (with a variety of job titles, such as kaitiaki) but others were colleagues who happened to be Māori, and external providers such as the staff in Māori health clinics. Although clinicians and managers appreciated receiving assistance from Māori colleagues, they described many challenges.
Some participants felt limited by restrictions on what kaitiaki could do. One SLT was frustrated because kaitiaki attended therapy sessions but would not translate or interpret into te reo Māori. Another said “The Māori support workers are there in terms of tikanga and stuff, but not that really specific stuff that we need in terms of an assessment or therapy programme”.

For SLTs working with kaitiaki, time was one of the biggest challenges. One manager described kaitiaki as “like gold dust” – precious but rare. Some participants expressed dissatisfaction, making comments such as “sometimes they’re not very available” and “they run on their own time, and they’ll be there when they’ll be there”. There were also difficulties in building relationships with kaitiaki. Some SLT managers accepted responsibility for this, making statements such as “I’m not blaming them, I’m saying look, I haven’t actually made the first step” and “we’re trying to engage but we are only trying to engage in a Pākehā way, we’re not trying to engage in a Māori way”.

In the absence of Māori SLTs, many clinicians and managers expressed a desire for a Māori colleague who was part of their team and understood SLT. Participants suggested providing basic SLT training for a cultural advisor who could then work with Māori with aphasia. Alternative ideas were having a cultural advisor run their reflective practice sessions or act as a mentor, “A person that I could reliably access… who knew their tikanga inside out, who lived in the Māori world and who had time to actually talk to me and invest in my learning and my understanding”.

A specialised “human resource” is te reo Māori interpreters and translators. When patients opted to receive aphasia therapy in a te reo Māori medium, SLTs found it difficult to access interpreters to use during sessions and translators to create resources such as communication books. Some regions did not have access to a te reo Māori interpreter. Even when translators were available, financial restrictions made it impossible to employ someone to translate resources into te reo Māori. These limitations meant that in most situations therapists relied on family members to assist with interpreting. They reported family being happy to help with this.

**Non-human resources**
Managers, in particular, recognised the financial difficulties involved in tailoring services for Māori with aphasia. They found it difficult to prioritise Māori with aphasia when they are a relatively small group and there is no evidence to determine “best practice”. One manager (who did not have control over budgets) said “Money is determined by population...
and… it wasn’t a massive population so it was kind of like, ‘well, you’ll just have to make
them fit with our dominant model’”

While managers were concerned about the allocation of funds, many of the clinicians felt
that time pressures impacted on their ability to provide an accessible and culturally safe
service for Māori. Participants recognised that time is required to build a relationship with
patients and whānau and to set goals collaboratively. In addition, because most SLTs were
working cross-culturally, they acknowledged the need for extra time to undertake PD, seek
cultural advice and find appropriate resources.

Some participants were able to take the time that was needed. One manager said “you could
say not having time is a challenge, that’s not the case. You prioritise what’s important” and
one clinician said “I probably book out an hour and a half rather than an hour with a patient,
just so that I’ve got more time with them”. However, many others felt very restricted by a
lack of time and high workloads. Their perception was that the elements that make therapy
culturally safe were the added extras, for which there was insufficient time. One SLT
explained:

At the moment it’s really just seeing as many patients as possible … and there isn’t
really time to stop and think about doing things outside the box or providing a
service in a different way.

Many of the participants felt limited by a lack of, what one clinician called “Kiwi-friendly”
assessments and therapy resources. Participants were not aware of any formal assessments
in te reo Māori and one recognised that some of the items in English language assessments
such as the Boston Naming Test are not familiar to Māori. Some SLTs recognised the
problems inherent in translating English resources into te reo rather than creating resources
based on a Māori world view.

One manager believed that the lack of resources was not necessarily a limitation -“If you
really are actually listening to that person’s story, working out what it is that they want to
do, you can be creative with your therapy”. However, participants’ concerns about limited
time suggest that such creativity is not always an option. In the absence of culturally-
appropriate formal resources, participants used resources such as workbooks from te reo
Māori courses they had attended. When providing therapy in te reo Māori, clinicians
experienced difficulty obtaining translations of documents because of regional variations in
vocabulary and grammar and the aforementioned problems with employing translators.
Combining the three factors
This section has provided a parallel description of SLTs’ accounts of current service provision for Māori with aphasia and their concepts of an accessible and culturally appropriate service. Both are incorporated in the three factors (“SLT factors”, “Ways of working” and “Resources”). These factors are related and overlapping, as illustrated in figure 3. The overlap between “SLT factors” and “Ways of working” is the concept that people make up a workplace and determine its culture. The overlap between “Ways of working” and “Resources” is the fact that workplace culture influences the way resources are used and the way the workforce behaves. The overlap between “Resources” and “SLT factors” is the managers who decide how to use resources and the people who deliver the service. The centre where all three factors overlap is the service provided for Māori with aphasia. Figure 3 can be used to illustrate both current service provision and the ideal “accessible and culturally appropriate” service, depending on the content of the factors that constitute it. If the content of the three contributing factors is current practice the centre represents the service currently provided. If the content of the contributing factors is culturally safe practice the centre result will be a service that is accessible and culturally appropriate.

Figure 3 SLT service provision for Māori with aphasia represented by three overlapping factors
Discussion

SLTs in New Zealand are obligated to provide a service that is “accessible to and culturally appropriate for disabled Māori and their whānau” (Minister for Disability Issues, 2001, p. 25) but have little guidance as to what such a service entails. Results of the current study showed that the service provided for Māori with aphasia is made up of three factors – “SLT factors”, “Ways of working” and “Resources” (human and non-human). This discussion will focus on the ways in which all three together determine the service provided and the implications this has for the SLT profession in New Zealand.

Campinha-Bacote (2002, p. 182) states that the cultural competence of a clinician is determined by five “constructs”. “Cultural awareness” involves being aware of one’s own professional and cultural background and the impact it will have on their service provision. “Cultural knowledge” involves building a knowledge base about diverse cultural groups. “Cultural skill” is the ability to collect appropriate and relevant information from clients of diverse cultures and ethnicities. “Cultural encounters” are the cross-cultural interactions one has with clients. Finally, “cultural desire” is the clinician’s motivation to engage with cultural competence because s/he wants to rather than because s/he has to. These five constructs were all evident in “SLT factors”, although the purpose of this series of interviews was not to evaluate the cultural competence of the participants.

Several SLTs recognised that an inability to speak te reo Māori was a limitation in their practice and reported a language barrier when delivering therapy for people who speak te reo Māori. Previous research (Centeno, 2009; D’Souza et al., 2012) has identified barriers associated with SLTs not speaking the client’s language, having limited access to interpreters, no access to clinicians who speak the client’s language, and very limited assessment tools in languages other than English. All of which were identified by participants in this study. However, therapists in the current study also acknowledged that they were infrequently called on to deliver therapy in a Māori medium. This calls into question just how much of a barrier it is for a therapist who does not speak te reo Māori. It is undoubtedly important for a service to be able to provide therapy in te reo Māori, and this must not be understated. However, one must consider the possible reasons for the disproportionate emphasis clinicians placed on te reo Māori. There is a big difference between acknowledging a lack of language ability and acknowledging a lack of cultural competence. It is easy for a clinician to acknowledge that she does not speak a language, and it is socially and professionally acceptable to do so. It is much more difficult for her to
acknowledge that she is not culturally competent or that she does not understand a culture that is indigenous to her country of residence or citizenship.

If a clinician is at an advanced level of cultural competence, is working in a culturally safe way and is truly undertaking whānau-centred practice, the lack of linguistic ability should not necessarily be a major limitation. A clinician who is all of these things could interact appropriately and could be aware of what s/he does not know, but not paralysed by it. S/he should then be able to make the most of the situation to source interpreting assistance in whatever way possible. This is not to downplay the importance of training more SLTs who are able to conduct therapy in te reo Māori. It is to emphasise that, as Roger (1998) claimed, an integration of social, cultural and linguistic dimensions is required, and to suggest that the inability to speak a language is not an acceptable excuse for failing to provide such a service.

A discussion about the use of interpreters is not complete without considering the reasons why few clinicians are called upon to provide therapy in te reo Māori. In the 2006 census (latest figures available), 23.7% of Māori could converse in te reo, with a higher proportion of speakers in the older age groups (McClintock, Mellsop, & Kingi, 2011). Although ability to speak te reo Māori does not equate to requesting service provision in te reo Māori, based on the census figures one could expect about a quarter of all Māori with aphasia to request therapy in te reo. Clearly this is not happening. Although clinicians claim that they offer to provide therapy in Māori, it is likely that Māori with aphasia sometimes turn it down because of the practicalities of receiving therapy in a language that the clinician does not speak, and in which there are no formal assessments or therapy resources. Some clinicians reported whānau members of people with aphasia being happy to assist with interpreting. The use of family as interpreters is not advised because they have emotional involvement in the situation (Roger & Code, 2011) and are not necessarily familiar with specialised terminology (Campinha-Bacote, 2002). It is possible that, rather than being genuinely happy to interpret, whānau were resigned to do it because they believed it was the only way to achieve what their loved one needed. While whānau should have the option of being involved in therapy, it is not their responsibility to provide interpreting services to make up for shortfalls in service provision.

Many participants spoke of the need for patient-centred or whānau-centred care. If an SLT is truly practising whānau-centred care then it will be culturally safe, for people of all cultures. For some participants, acknowledging that all Māori are different and everyone is
an individual seemed to be paralysing. They were aware of the need to provide culturally safe services but paralysed by the knowledge that every person sees culture differently and that one should not practise “stereotypically” (Ramsden, 2000, p. 7). The concept of intra-ethnic variation is that “there is more variation within a cultural group than across cultural groups” (Campinha-Bacote, 2002, p. 182). Clinicians might be better able to proceed if they were familiar with the five constructs of Campinha-Bacote’s model and the knowledge that intra-ethnic variation is only part of it. One can have a high level of cultural competence, recognise intra-ethnic variation, and still proceed with targeted interventions for Māori. Once this is clear, statements such as “everyone’s an individual” and “you can’t generalise” fade into the background, along with the inability to speak te reo Māori.

The support of Māori colleagues is essential if SLTs are to work in a culturally safe manner. Participants in this study identified the small number of Māori SLTs as a barrier to the provision of accessible and culturally safe services for Māori with aphasia. This is an issue that SLT training programmes need to address. In the meantime, participants identified the need for Māori colleagues who could support them in their work. Some participants thought that “I could train them” while others thought “they could train me”. The former approach must be treated carefully. Ramsden (2000) cautioned against “the ‘unqualified’ or second level Māori health worker, as support to the non-Māori health professional” because it “does not lead to tino rangatiratanga”. The differing approaches that participants took were most likely indicative of their differing needs (providing therapy in te reo Māori versus PD), although possibly indicative of their underlying attitudes towards whether they personally needed training. Participants acknowledged challenges in relating to Māori colleagues and some managers recognised the part they had to play in this (“we’re trying to engage but we are only trying to engage in a pākehā way, we’re not trying to engage in a Māori way”).

There are challenges inherent in this situation. Clinicians and managers need assistance from Māori colleagues to increase their cultural competence. However, in a medical-model system with little time for building relationships, SLTs’ fledgling cultural competence is insufficient to enable them to engage with Māori colleagues in the first place.

Participants cited time and funding as limiting their service delivery for Māori. The general perception was that working with Māori in a culturally safe manner was an added extra and therefore the first thing to be lost during busy periods. This was illustrated by the SLT who said “there isn’t really time to stop and think about doing things outside the box or providing a service in a different way”. It is a concern that providing a culturally safe
service for Māori is classed as “different” and “outside the box”. Funding and time are limited, but this is not innately problematic for service delivery for Māori with aphasia. It is a problem only because, despite the rhetoric, the healthcare system does not allow employees to easily work in a culturally safe way with Māori. This might also provide insight into why clinicians perceived kaitiaki to not have enough time. Kaitiaki are expected to work in a Māori way within a system that is not compatible with a Māori way of working. *HKO* and the *NZDS* demonstrate that working with Māori in a culturally safe way is core business rather than an added extra. Therefore, systems should be structured to reflect this. It is likely that such a way of working would not only benefit Māori, but all people with aphasia. One manager stated this while describing ideal service provision for Māori:

> I can’t remember who it was who said this, but I do really believe that if we get it right for Māori, we’ve got it right for everyone. So I don’t actually feel I’m describing an exclusively Māori service, I think I’m actually describing best practice.

Many of these issues are not unique to aphasia or Māori but have been noted in other areas of Māori health research and the broader aphasia community. Curtis et al. (2010) identified the roles of society, policy, and the clinician in reducing inequalities between Māori and non-Māori in ischaemic heart disease. Australian SLTs have identified challenges similar to those revealed in this study including an emphasis on dysphagia (swallowing disorder) rather than aphasia in the acute setting, high workloads, inflexible service provision and a lack of confidence in working with “culturally and linguistically diverse” clients (Rose et al., 2013).

Regardless of the way a team works, the policies they adhere to, and the resources available, individual clinicians are not going to provide a culturally safe service for Māori with aphasia if they have low “cultural desire”. Campinha-Bacote (2002, p. 183) explained the importance of “cultural desire”:

> It is not enough for the health care provider to merely say they respect a client’s values, beliefs, and practices or to go through the motions of providing a culturally specific intervention that the literature reports is effective with a particular ethnic group. What is of grave importance is the health care provider’s real motivation or desire to provide care that is culturally responsive. Cultural desire includes a genuine passion to be open and flexible with others, to accept differences and build on similarities, and to be willing to learn from others as cultural informants.

“Cultural desire” is similar to what kuia have called “he ngākau pai” (a good heart) or “he wairua pai” (a good spirit). It is largely intangible but kuia and kaumatua can usually gauge
it. “Cultural desire” is not something that can be easily taught. Some SLTs will enter training with existing high levels of it, while others will not gain it, regardless of the training they have received.

So how do we work towards culturally safe service provision for Māori with aphasia? And how can we evaluate whether we have achieved it? SLTs in this study identified the need for a means of evaluating both the cultural competency of clinicians and the service provided for Māori. One manager was already attempting to measure outcomes in a Māori way by using Te Whare Tapa Whā, although she acknowledged the challenges inherent in that.

An evaluation of cultural competence and the cultural safety of service provision is innately complex and, as much as managers would like to have a checklist, it cannot be reduced to one. Because the service provided is made up of “SLT factors”, “Ways of working” and “Resources”, evaluating or changing the service will take place at the level of any one of the contributing factors. The NZSTA Programme Accreditation Committee has proposed a set of Cultural Competency Measures for Entry Level Students as a way of determining students’ cultural competence. The creation of this document shows “cultural desire” within the profession of SLT. Although the document is designed for SLT students, when it is widely available it will also be a useful resource for practising SLTs to use to guide and evaluate their own cultural competence.

**Conclusion**

In this article we have described current service provision for Māori with aphasia, and SLTs’ concepts of an accessible and culturally appropriate service. In addition we have provided insight into the underrepresentation of Māori with aphasia on SLT caseloads.

The results show that SLTs want to provide a service that is accessible, culturally safe and culturally appropriate for Māori with aphasia, but there are many limitations on their practice. These include clinicians’ lack of knowledge, varying levels of cultural competence among clinicians, small numbers of Māori SLTs and Māori colleagues available to help, and systems in which working in a culturally safe way is considered an added extra. Because “cultural desire” (Campinha-Bacote, 2002) is present in some individual SLTs, and in the profession as a whole, it is possible, although difficult, to make changes to the service provided for Māori.
References


Chapter 7: Conclusion

In this concluding chapter we summarise and integrate the findings of all previous chapters, consider the challenges faced in the research, and draw conclusions about the ways in which the overall results can be used to inform current practice and future research. Finally, the thesis concludes as it began, with a personal reflection.

Summary of the findings

This study explored aphasia and SLT from the perspectives of Māori with aphasia, whānau members and SLTs. A structured review of the literature revealed no articles about Māori with aphasia, but several documents (The NZDS, NPR and HKO) demonstrating a strategic commitment to improving health and disability outcomes for Māori. This provided the impetus to investigate current service provision for Māori with aphasia, from the perspectives of service users and SLTs.

In Chapter 3 the strengths and challenges of combining KMR and ID were described, demonstrating that this approach was critical to the research. Although KMR and ID come from different paradigms, when they are brought together they complement each other by each filling gaps left by the other. KMR ensures that the research is decolonising and transformative. ID acknowledges the role of the SLT and the influence of disciplinary knowledge. The combination of the two approaches overcomes many of the methodological challenges inherent in research undertaken with Māori with aphasia and enables SLTs and Māori with aphasia to learn from each other. The important and potentially transformative findings of this thesis would not have been possible without this novel research approach.

Chapter 4 provided insight into the experiences of Māori with aphasia and their whānau members. While “Grieving for what is lost”, people with aphasia and whānau members also “Recognis[e] what we’ve got”. There is a tension between grieving for what has been lost with the aphasia and being grateful for what remains or has been gained since the stroke. Whānau demonstrated that “It’s hard” living with aphasia, and described many negative emotions. In those difficult circumstances, whānau showed that “We can choose how to respond” as they actively managed communication and rehabilitation.

Chapter 5 showed that, while some Māori with aphasia receive a service that is accessible, appropriate and culturally safe, others do not. The clinician plays a key role in building the mutually respectful therapeutic relationship that is vital for successful aphasia therapy. This
provides the foundation for a collaborative therapy process, in which whānau are supported to undertake their rehabilitation in a way that suits them, using resources that affirm their identity.

In Chapter 6, SLT clinicians and managers revealed three factors that together constitute the service provided for Māori with aphasia. These are “SLT factors”, “Ways of working” and “Resources” (human and non-human). SLTs described many limitations on their practice, including their own lack of knowledge, varying levels of cultural competence, small numbers of Māori SLTs and Māori colleagues available to help, and systems in which working in a culturally safe way is treated as an added extra rather than core business.

Challenges

Challenges arose in this study when the reality of conducting KMR with people with aphasia was different to the ideal. KMR is often undertaken in partnership with a Māori community and supervised by kaumātua from that community (Rāwiri, 2011; Walsh-Tapiata, 2003). There are a relatively small number of people with aphasia in New Zealand, and an even smaller number of Māori with aphasia. Any one iwi, hapū or community is unlikely to have more than a few people with aphasia. A community of sorts arose from this research. It is a broad community of interested parties including Māori with aphasia, whānau members, Māori and Indigenous researchers, and SLTs. The community that has formed around this research has been formed through connection with a university and the public health system. This is not ideal for KMR because it aligned the research with these institutions rather than with the Māori world (Irwin, 1994). It would have been preferable to meet people through their whānau and iwi rather than through the health system. Unfortunately this was not possible because attempts to recruit participants through Māori networks, marae, and Māori health providers did not result in sufficient participants. The consequent need to recruit participants through SLTs meant that all participants had been involved with the public health system and all had received SLT.

Walker et al. (2006) recognised that, although KMR aims to revitalise te reo Māori, and it is not possible to access some concepts in an English medium, the less-than-ideal reality is that KMR is often undertaken in a mix of English and te reo. That was the case for this research. The researchers, and most participants, were not fluent speakers of te reo Māori. Two participants were fluent speakers who used te reo in their daily lives. A third had spoken the language as a child but not since she left home. Within interviews there was code-switching.
and the use of Māori words without translations. Whānau members translated into te reo Māori for the person with aphasia when necessary to aid their understanding. Whaea Kaanga, the kuia for the project, pointed out some of the limitations created by conducting the research in English. When she looked at the mat model of aphasia she talked about the concepts represented in the mat being much bigger than the words that are there. She added that the words, and therefore concepts, would be different if the research had been undertaken in te reo Māori. For example Whaea suggested that the word “sadness” is too small to encompass the emotion associated with stroke but it is better captured in the word “mate”. Where the mat has the word “embarrassment”, Whaea suggested that “whakamā”, which is more than embarrassment, would better describe the concept. None of the participants used the word “whakamā” in their kōrero, although some of them described the concept. It is possible that participants wanted to use the word “whakamā” but chose not to because they thought the researcher might not understand it, or because they were in an English-speaking context.

In the interviews with people with aphasia and whānau members, one of the questions was about how aphasia affected the whānau spiritually. It was difficult to explain this question to participants and the first few families struggled to answer it. Taking a very academic approach to the situation, we discussed other ways to ask the question and alternative words to use in place of “spirituality”. When we did not come up with a satisfactory solution, we asked Whaea Kaanga for advice before scheduling any more interviews. Whaea’s approach was very different to ours, and it demonstrated the importance of wisdom and guidance from elders in Māori research. Whaea said that “some people wait for you to open the door to acknowledge wairua (spirit)”. Given this, she recommended we offer to open the interview with a karakia (prayer) and then gauge the group’s response, gently discovering their level of comfort with spirituality and the Māori language. Whaea Kaanga emphasised the need to for the interviewer to “warm” herself, the home, and the family through the opening mihi (greeting). Before speaking directly about spirituality, the space must be prepared so that everyone is in a good position to enter the discussion.

Several people recommended that, when kaumātua were being interviewed, a kaumatua should conduct, or at least assist with, the interviews. This is because the kaumātua can converse in te reo Māori and understand each other at a level that is only possible between people of the same generation. This was very important advice. One occasion arose in which a kaumatua from the same iwi could have been involved in the interview.
Unfortunately, because of the heavy demands placed on present-day kaumātua, it was not possible to schedule a time at which everyone was available.

During the research planning there was some discussion about interviewing whānau groups. At that time the results of the large “Researching with Whānau Collectives” project by Cram and Kennedy (2010) were not yet available. In the research planning it was not clear whether a whānau interview should be treated as a focus group and whether the voices that are heard in a whānau interview are those of the individuals within the group or the whānau as a whole. This dilemma was solved through conversations with Māori colleagues, one of whom said the whānau sat round the kitchen table and had a kōrero and they all contributed as they wished. They did not seem to see “voice” as an issue. In addition when “Researching with Whānau Collectives” (Cram & Kennedy, 2010) was published, it did not address this issue of “voice”. The combination of colleagues’ opinions and research demonstrated that the concern about the voice of the whānau versus the individual has arisen from a non-Māori point of view. Therefore, as the research progressed, it became a non-issue and the kōrero of individuals and whānau flowed naturally, sometimes as a collection of individuals and sometimes as a whānau.

**Diversity of participants**

Throughout the interviews with people with aphasia and whānau members, it was evident that the group was extremely heterogeneous. Participants with aphasia covered an age range of more than 25 years and were from a variety of living situations and socioeconomic backgrounds. It is, therefore not surprising that they described a wide range of experiences of aphasia. The mat model captures the experiences of this group of Māori with aphasia and whānau members, as much as is possible to encompass the experiences of such a diverse group. It shows that, for all the diversity, the human experiences of love and loss are part of aphasia for almost everyone. During the interviews with SLTs, many participants spoke about the wide range of identities in the Māori clients they work with. Some SLTs used this diversity as a reason why it is not possible to create aphasia interventions tailored to Māori. The diversity of this cohort means that the findings are applicable to a wide range of Māori with aphasia. Furthermore, SLTs should see this as a strength and need not be paralysed by intra-ethnic variation (Campinha-Bacote, 2002).
Bringing it all together

True to ID and Indigenous research, the experiences of a group of people cannot be said to represent anything more than the experiences of those involved. Nevertheless, when the findings of the interviews with SLTs, Māori with aphasia and whānau members are brought together, they illustrate the current state of aphasia for Māori in New Zealand, within the confines of the methodologies used.

The mat (figure 1), woven from the experiences of Māori with aphasia and whānau members, is the story of life with aphasia. As such, it is the context for the findings about language therapy that are summarised in figures 2 and 3. The mat demonstrates that, although aphasia is big, life is bigger. In some ways one could conclude that SLT is only a small part of life with aphasia, because it is mentioned in only a few strands of the mat. This conclusion could then lead to the decision that SLT should remain only a small part, because there is much more to life with aphasia than SLT. An alternative, and more feasible, conclusion is that SLT is woven throughout the entire mat. It is impossible to separate, for example, “working out communication strategies” from the conflicting feelings of grief and gratefulness that are interwoven with this strand. An SLT who tries to address strands such as “working out communication strategies” and “learning about stroke and aphasia” without recognising that they are part of a much bigger picture is unlikely to succeed. The whole mat could be seen as aphasia and, given that SLTs address the entirety of aphasia, there is no strand that is irrelevant to the SLT. It follows that, when considering aphasia therapy from the perspectives of clinicians and Māori with aphasia, it must remain in the context of the mat. Aphasia therapy is not something separate from life (the mat), it happens within it and is part of it.

Given that aphasia therapy is an integral part of the mat, it should not be surprising that the findings of the interviews with SLTs, and the Māori with aphasia and whānau members who spoke about their experiences of SLT, are rather similar. Both focused on the same thing (aphasia therapy) in the same context (the mat), albeit from different perspectives and world views. SLTs and whānau with aphasia revealed the importance of recognising the world view of the person with aphasia and whānau, conducting therapy in a culturally safe way, in an appropriate location, using appropriate resources, and building a good therapeutic relationship. The positive and negative experiences of aphasia therapy described by both whānau with aphasia and clinicians showed that at present, while some SLT services and individual clinicians incorporate all these factors to provide an accessible and culturally
appropriate service, others do not. It means that the experiences of language therapy vary greatly, depending on where in New Zealand the person with aphasia lives, and which clinician s/he happens to be allocated to.

**Aphasia and cultural context**
Throughout this research, academics and clinicians often asked “what’s different about what you’ve found?” and “these findings look to me like you’ve just described aphasia. What’s uniquely Māori about this?” The motivation behind these questions was not always clear. One consultant physician explained his reasoning when he suggested that, if one could demonstrate that Māori whānau experience aphasia “like everyone else”, then there would be no need to change current service provision for Māori. This comment illustrated the risk that, if the research did not demonstrate, and constantly emphasise, that Māori with aphasia are unique, it could be used as evidence that Māori experience aphasia “like everyone else”. Assuming this physician is not alone in his attitude, this could lead to poorer service provision for Māori, rather than the intended improvements.

KMR places Māori at the centre, with no need to make comparisons with other groups. This, coupled with concern that the conclusions could be misconstrued as demonstrating no need for culturally appropriate services, led to a staunch refusal to compare Māori experiences of aphasia with those of any other group. In a final visit to discuss the findings with Whaea Kaanga, it became clear that this refusal to make comparisons was unnecessarily, and inappropriately, confining the research. Whaea suggested that the participants would be proud to have contributed to the “mixing bowl” of aphasia research. She asked “see if you can match it up [with existing aphasia research]” and added that “Māori suffer exactly the same”. Whaea said that the participants should be given the opportunity to be part of the bigger picture. Her most salient piece of advice was that this research was not going to enhance the Māori world but the aphasia world.

Whaea Kaanga’s advice presented a challenge. In KMR there is no need to compare Māori to others, but the wishes of the participants and the advice of a kuia are valued. At this point, the philosophy of KMR and the advice of the kuia appeared to be in conflict. Further analysis revealed that there is in fact no conflict. The refusal to make comparisons is correct to a point. Comparisons must not be drawn in a way that treats Māori as “other” or, as in the case of the consultant physician, motivated by wanting to treat everyone the same. However, as Whaea wisely pointed out, refusing any further comparison would unfairly remove from Māori the opportunity to contribute to the wider understanding of aphasia.
Some aphasia experiences are likely to be shared across individuals and cultures, particularly emotions such as loss, grief and frustration. The main themes of the experiences of Māori with aphasia and whānau members were grieving for what is lost while recognising what one has, and struggling with a hard situation and choosing how to respond to it. Elements of these are likely to be common to all people with aphasia and family members. Connie’s daughter acknowledged this when she said:

We still have Mum and we’re all grateful but we’ve had to experience loss as well… [starts crying] And we do mourn that not just for Mum’s sake, but also our own… I don’t know if that’s relevant to being a Māori family but I think it would be relevant for everybody

This research indeed enhances the wider understanding of aphasia, but it is much more complex than the consultant physician realised. In his quest to show that Māori experience aphasia “like everyone else”, he had not taken account of the differences that arise at the societal level. Although the basic human experience of aphasia may be similar, the context in which the person with aphasia lives makes a difference. When it comes to experiences of aphasia and aphasia therapy it is futile to try and separate them from culture and society. Legg (2010, p. 240) explained this in relation to the experiences of adults with aphasia in a South African township – “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”. This could be said of any person with aphasia, anywhere in the world. It is similar to the findings of Curtis et al. (2010), who described the roles of society, policy and the clinician in reducing inequalities in ischaemic heart disease in New Zealand.

Makere’s son demonstrated the influence of society on the experiences of aphasia when he spoke about the way aphasia might be experienced in a traditional marae environment. He had described the ageing process on the marae and when asked if aphasia might be experienced differently there. He replied:

I think so. I actually think so… During our experiences on the marae… you would always have old people who were dottery and you knew the ones who didn’t really make sense and… there was more caring going on I think… Back then it was quite a thing to see nephews, nieces, and mokopuna just sitting with the old people. Even if they knew the old people couldn’t talk much or even if the old person was 90% of the time asleep, dozing, you know, they would still be there. And there’s hands on, it’s a bit like healing hands, there’s constant touching. It’s just a different environment, different atmosphere… there’s no equivalent here. I live a very
European Westernised life. We’ve got a section, a property, I barely know the guy next door type of thing… Your interaction with the community is very insular. You’re self-contained units here… but if we were living in [home region], shucks I would know people 20 km down the road and you’d know every single thing that’s going on in their house… Well the difference is it’s Māori world-Pākehā world (if you want to put it that way) and we live in a Pākehā world so we’re very assimilated.

The societal impact on Māori experiences of aphasia and aphasia therapy arises from living in a colonised society. Pākehā New Zealanders who acquire aphasia, and receive therapy, are served by a health system that was set up to suit people of their culture. They are likely to have an SLT who is of European origin (most likely Pākehā, but possibly from another country with European cultural background) and trained in a Western university. The common cultural background between the person with aphasia and therapist makes it relatively easy to develop the good therapeutic relationship that is so important for therapy. Although the lack of New Zealand-specific therapy resources means they might have to use resources from Britain or the United States, the language is more-or-less the same and the cultural focus is similar. In contrast, Māori who acquire aphasia, and receive therapy, are treated in a health system that was not designed for them. Although efforts are made to make the service culturally appropriate and safe, the reality is that it is not a Māori system. Their SLT is unlikely to be Māori, so the therapeutic relationship will need to be negotiated cross-culturally. Even if the SLT is Māori, s/he will have trained in a mainstream university and will be working as part of a health system which is not run on Māori values. Therapy resources that acknowledge a Māori world view are not readily available, and neither are resources in te reo Māori. If they would like to receive language therapy in te reo Māori it will most likely be through an interpreter, if an interpreter is available.

**Government documents**

Justification for this research came from the commitment to improving health and disability outcomes for Māori that is demonstrated in *HKO* (Minister of Health and Associate Minister of Health, 2002), *The NZDS* (Minister for Disability Issues, 2001) and *NPR* (Health Research Council of New Zealand, 2010). It is, therefore, worth considering how this research has addressed the aims of these documents.

**He Korowai Oranga**

With a holistic approach to wellness, *HKO* aims to support whānau as they take control and improve their own health. It emphasises “the importance of working with people in their social contexts, not just with their physical symptoms” (p.1). The need to work with Māori
with aphasia in their social context has been clear throughout the interviews with Māori with aphasia and with SLTs. This research reinforces that for clinicians and decision-makers. Treaty of Waitangi principles of partnership, participation and protection are woven throughout HKO. Partnership involves working with Māori communities to improve health outcomes and health services. Participation enables Māori to contribute to, among other things, development of services. Protection aims for Māori to enjoy the same health status as non-Māori and seeks to safeguard Māori practices and values.

These principles have been applied in the research, which at the same time has demonstrated how HKO can be realised in aphasia research. The research was conducted with the Māori aphasia community. Although the results of the research are yet to be implemented to improve services and outcomes, it has laid the foundation for future research with that focus. This research, which contributes to the development of services, has involved Māori at every stage of the research process. Communication is intertwined with health, as demonstrated by Te Whare Tapa Whā (Durie, 1998). Not only is communication necessary for nurturing healthy relationships, it is also important for engaging with the health system in order to receive healthcare. Describing the experiences of Māori with aphasia has shed light on their current health status and access to health care. Language (especially te reo Māori) is both a cultural value and practice and a means through which to express cultural values and practices. As such, addressing the issue of aphasia for Māori addresses the commitment to safeguarding Māori cultural values and practices.

**The New Zealand Disability Strategy**

Objective 11 of the NZDS aims to “promote participation of disabled Māori” (Minister for Disability Issues, 2001, p. 25). The action point “establish more disability support services designed and provided by Māori for Māori” is not a realistic goal for SLT for aphasia at the moment. This is because of the small size of the profession and the small number of Māori SLTs working in health. However, all SLTs can work towards “ensur[ing] mainstream providers of disability services are accessible to and culturally appropriate for disabled Māori and their whānau”. In elucidating Māori experiences of aphasia and aphasia therapy, and SLT experiences of aphasia therapy with Māori, this research is already contributing towards making SLT services for Māori with aphasia more accessible and culturally appropriate. In addition, it has laid the foundation for further research to continue improving services in this regard.
Ngā Pou Rangahau
This research has specifically addressed two of the objectives of NPR (Health Research Council of New Zealand, 2010). Goal 1 is “Transforming Māori health research knowledge and practice”. An objective of that goal is “to build an evidence base which contributes to improved Māori health outcomes”. The knowledge about Māori experiences of aphasia and SLT perspectives on aphasia therapy for Māori that this research has created an evidence base for aphasia therapy where previously none existed. Goal 3 is “Translating research into Māori health gains” and it includes an objective “to build a research evidence base which can be effectively translated into improved health outcomes for Māori”. Now that this research has built a preliminary evidence base about Māori experiences of aphasia, future research can focus on translating this into Māori health gains.

Recommendations for practice and for future research
The aim of this research was to describe current experiences, not to create a clinical intervention. However, some clinical implications arose during the study and these are reported here. SLTs working with Māori with aphasia need to recognise:

- The ways in which the clinician, resources, and ways of working impact on service provision for Māori with aphasia (as depicted in figure 3). Cultural competence training may allow clinicians to recognise and discuss the way these factors impact upon their practices for Māori with aphasia
- The context that is the broad and complicated experiences of Māori with aphasia and whānau members, and the tensions within these experiences (as represented by the mat in figure 1). When working with Māori with aphasia and their whānau, SLTs could use the mat to begin conversations about areas to address in therapy.
- The importance of a good therapeutic relationship for aphasia therapy with Māori whānau, and the impact that world view, resources used and therapy setting have on that relationship (as illustrated in figure 2). Again, cultural competence training that incorporates these concepts may enable clinicians to develop culturally-safe relationships. The use of appropriate resources and therapy settings may also promote better relationships.
- That aphasia happens within a cultural and social context. Māori do not experience aphasia in an exotic way but their experiences of aphasia cannot be separated from the social and cultural context of a colonised society.
• The fact that Māori experiences of aphasia are not especially unique does not mean that all people with aphasia should be treated the same within the health service. Similarly, the diversity of Māori does not prevent consideration of culturally safe service delivery.

However, recognition alone is insufficient; it must lead to changes in clinical practice. Future research will focus on the application of these concepts, working with Māori with aphasia, whānau members and SLTs to design, implement, and evaluate an intervention for whānau with aphasia. Before this can be undertaken, it is necessary to agree on the desired outcomes and validate a tool that can be used to measure these (Harwood, 2010). Future research will be rooted in the findings of the research undertaken for this thesis. On the final visit to discuss the research findings with Whaea Kaanga she emphasised the preciousness of the kōrero from the participants. Whaea impressed the need for the findings to be returned to the participants; they have given enough for the research to move forward and make changes, and they need to see wide ranging benefits from what they have given. KMR must make a positive difference for Māori (Pihama, 2011) but Whaea Kaanga went a step further than that. She said that this research should benefit not just Māori but all people with aphasia. This suggests the possibility of research arising from this study being applied to anyone with aphasia.

Conclusion

This project started with the clinical observation that few Māori with aphasia were receiving SLT and the knowledge that SLTs had an obligation to provide an accessible and culturally appropriate service for this group. In addition, there was no literature about how Māori whānau experience aphasia or the SLT service that is currently provided, and no methodology suitable to use in research to address these knowledge gaps. Before any changes could be made to the service provided, it was necessary to document and analyse the current situation, from the perspectives of Māori with aphasia, whānau members and SLTs. Before this could be researched it was necessary to create a methodological approach suitable for the task in hand. This thesis has addressed these knowledge gaps.

Because this study did not directly address the number of Māori with aphasia receiving SLT, conclusions about this cannot be drawn. However, the research has provided further information that begins to address the issue. Interviews with SLTs and managers working with Māori with aphasia across New Zealand revealed the current state of therapy provision.
for Māori with aphasia, and SLTs’ concepts of ideal service provision. They showed that SLTs are aware of the need to provide a culturally-safe service for Māori with aphasia but face many barriers in doing this. The interviews also provided evidence that Māori may be under-represented on the caseloads of SLTs in some areas. Small numbers of Māori with aphasia receiving SLT could indicate either that therapy is not required because aphasia is not a problem, or that SLTs are not offering or providing therapy in the right way. The interviews with whānau with aphasia confirmed that, while Māori experiences of aphasia are many and varied, aphasia can have a devastating effect on whānau (Chapter 4). This shows that aphasia is a problem for Māori. When whānau commented on the SLT service they had received it became clear that whānau do value SLT. This led to a critical analysis of aphasia therapy from the perspectives of Māori with aphasia and whānau members, which concluded that the success of aphasia therapy for Māori is dependent on a good therapeutic relationship (Chapter 5). Some participants’ experiences of aphasia therapy (both clinicians and clients) suggest that the small numbers on SLT caseloads might be because the service is not offered or provided in a culturally safe manner (Chapters 5 and 6). This thesis does not provide sufficient evidence to state categorically that Māori with aphasia are under-represented on SLT caseloads or that culturally-unsafe service provision is the cause. However, it calls SLTs to be aware that if Māori whānau turn down offers of SLT it is unlikely to be because they are not bothered by the aphasia.

Overall, this thesis has described the experiences of Māori with aphasia in New Zealand, from the perspectives of Māori with aphasia, whānau members, and SLTs. In addition, it has contributed the novel approach of using ID within KMR and shown it to be a useful tool for conducting clinically applicable research that is of benefit to both Māori with aphasia and clinicians. Like all people, Māori experiences of aphasia are shaped by the cultural and societal context in which they live. Although much of the focus was on the provision of an accessible and culturally appropriate service, that is a means to arriving at the ultimate aim, that is, whānau living well with aphasia. This aim is shared by Māori with aphasia, whānau members and SLTs and collaboration between the three groups is the only way to achieve it.

**Final Reflections**

These final reflections follow on from the personal context provided in the introduction as I look back at my journey over the past three-and-a-half years. As well as learning about KMR and Māori experiences of aphasia, I have learnt a lot about who I am and where I belong. Undertaking this research has given me many opportunities to live as Māori, for
which I feel very privileged. My first experience of living as Māori came at the Hui Whakapiripiri, shortly after the research began. The first day at the hui was unforgettable. I had walked into another culture. Not the culture that I’d seen on display in museums and at pōwhiri, but the way of being, thinking and doing, that is day-to-day contemporary Māori. Interactions, relationships, language, humour, everything was different, and I was included in it. At the end of the day I went to the supermarket and I felt culture shock like never before. I had stepped out of the Māori world and back into the Pākehā world. It was an ordinary everyday supermarket, but the contrast in culture was stark. That night I wrote in my journal:

I fluctuated today between feeling at home and convinced that my research is good and right, and feeling like an outsider and wondering why I am here… This is a whole new world and way of being. Do I want to enter it? Become part of it? There is so much good in this Māori world. I would like to be part of it. However, I noticed today that to be Māori is to carry a burden, the burden of colonisation. Do I want to take that on? I think in a way there is no going back. I’ve felt it so now I can’t ignore it. I have to do something with it. It’s one thing to look at the Māori situation in NZ and feel bad for “them”, as an outsider, and feel moved to do something about it. It’s something else to feel it in your heart because these are your people. I felt a glimpse of that today. I think it was the first time I actually felt Māori.

As my Māori PhD journey continued I was constantly challenged. I began to take on a Māori world view and slowly recognised the colonised and colonising areas of my thinking. I read a lot about KMR, but all that head knowledge was not very useful. I don’t fully understand concepts until I’ve experienced or felt them. (Un)luckily, a university provides plenty of opportunities for a Māori researcher to experience modern-day colonisation. My first such experience came when I presented my research plan at the University’s “Exposure” competition. In hearing the adjudicators’ comments I felt that my world view was not understood and the research was being judged by a set of values that did not fit with it. It was very much a clash of cultures. As I have already described, further opportunities to grow as a Māori researcher came when academics at the Psychology PhD students’ annual “in-house” presentations and consultant physicians at a hospital insisted on the need for a comparison group in the research with Māori whānau.

As my journey as a kaupapa Māori researcher continued, my quest to understand KMR took me to Kei Tua o te Pae hui in Wellington. Following a keynote presentation by Professor Linda Smith I realised something vitally important, as I wrote in my research journal:
If there were a charter or model or checklist that summed up KMR I could have taken it, quoted it, and not had to grapple with it, journey with it, and discover it. The whole experience would therefore be limited. As Linda Smith said, “I won’t tell you what it is because the point is that you discover it for yourself”

I had been looking for a concise definition of KMR. Something that my university-trained brain could file away neatly, something I could quote to sum up KMR quickly and easily. I was frustrated that I could not find this definition. It was only when I stopped looking for the definition that I realised I was well on the way to finding it.

Over time I became more confident as a kaupapa Māori researcher, and I learnt which forums would understand me and which would not. I stopped presenting in forums where I expected that people “wouldn’t get it”. Was that the right thing to do? I don’t know. I guess there was an element of self-preservation at play. I helped organise a “Fono Rangahau” in which the Māori and Pacific Psychology Research Group students presented our work in a symposium conducted in a Māori and Pacific way. It was wonderful to present in an environment in which no-one had to explain what KMR is, and it was taken for granted that students would be using an Indigenous methodology of some sort.

However, one should not always avoid presenting in unfriendly environments, and one cannot necessarily tell when an environment is going to be unfriendly. Towards the end of my doctoral studies I had an unexpected negative experience at a presentation skills workshop run by an external facilitator as part of the University of Auckland Doctoral Academic Career Module. At the end of the day each attendee had to demonstrate their newly-acquired presentation skills by delivering a “3 minute thesis”. The following passage, copied from my feedback to the module organisers, illustrates my experience:

After I delivered my 3 minute thesis the facilitator said “It’s interesting that you are doing this research when you are not Māori”. When I told her that I am Māori, she talked about how it would add credibility to the presentation if I said that during the presentation. I felt upset by these comments for two reasons: 1) I am Māori (although I don’t look it) and 2) I felt that I was being asked to justify why I am doing the research. No-one else was asked to talk about themselves and why they are “qualified” to do their research.

I am used to having to convince people that I am Māori (although Māori never question me about it) and I am used to having to justify why I am doing this research. However, I get tired of having to do these two things and it limits where I am prepared to present. I have been thinking about why the facilitator’s well-intended comment upset me. I think it’s because, although I am used to having to
justify myself elsewhere, I had hoped that this would be a safe place where that was not required.

And so the research continued. I completed the data collection and analysis (although it feels somewhat sacrilegious to call such precious kōrero “data”). Sue moved on and Matire completed her PhD and stepped up to be my supervisor. Then the discussions began as to what I needed to include in the thesis. Discussion centred on the need to make the thesis a complete document by bringing it full circle, linking it back to the original motivation for the research. The problem is, it is not possible to come full circle in this project because I have moved on from where I started. If I could go back and start again, knowing what I know now, I would do it all very differently. I started this research as an SLT and I am finishing it as a Māori woman. There have been many times when I’ve wondered why I chose this path. It would have been much easier to remain as a Pākehā researcher and do Pākehā research, but that’s not what I have been called to do. Towards the end of the writing process Clare asked me “is this a KMR thesis that happens to involve a bit of ID, or is it an ID thesis that is informed by a bit of KMR?” That is where the difficulty lies. That which started out as an ID study informed by KMR has become a KMR thesis that incorporated ID. The thesis I have completed is not the thesis I originally set out to complete. That is to be expected, because I am not the same person I was when I began writing it.

References


Appendices
Appendix B: Participant recruitment flyer, people with aphasia

Te mate ngaronga reo – Aphasia
Do you know someone with aphasia?

Aphasia is a language disorder, usually caused by a stroke. Aphasia affects a person's ability to communicate with others. People with aphasia may find it hard to:
- Talk
- Understand others
- Read
- Write
- Use numbers

We are looking for Māori who:
- have aphasia caused by a stroke (at least six months ago)
- have whānau (not necessarily Māori) who can participate in interviews
- are 18 years or over

We will arrange a kōrero (interview) with people with aphasia and their whānau to talk about living with aphasia.

Please contact us for more information:
Karen McLellan  (09) 923 4930  k.mclellan@auckland.ac.nz
Dr Sue Crengle  (09) 923 7866  s.crengle@auckland.ac.nz

Karen McLellan is from Ngaiterangi. She is a speech and language therapist and a PhD student at The University of Auckland.

This study has received ethical approval from the Northern Y Regional Ethics Committee

Version one: 17 March 2011
Appendix C: Participant information sheet, people with aphasia and whānau members

DEPARTMENT OF PSYCHOLOGY (Speech Science)

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

Building 721, Tamaki Campus
261 Morrin Road, Glen Innes
Auckland, New Zealand
Telephone +64 9 923 4930
Facsimile +64 9 373 7902
Email: k.mclellan@auckland.ac.nz
The University of Auckland
Private Bag 92019
Auckland, New Zealand

Participant Information Sheet

Research title:
The experiences of Māori with aphasia (language disorder) and their whānau

Researcher: My name is Karen McLellan. My iwi is Ngaiterangi. I am a speech and language therapist. I am doing a PhD at The University of Auckland.

Supervisors: My supervisors are Dr Clare McCann, Dr Sue Crengle, and Professor Linda Worrall.

Clare is a speech and language therapist. She is a lecturer at the University of Auckland.

Sue is a doctor. She is a lecturer at the University of Auckland.

Linda is a speech and language therapist. She is a lecturer at the University of Queensland, Australia.

Our contact details:

Karen McLellan  (09) 923 4930  k.mclellan@auckland.ac.nz
Clare McCann  (09) 923 5221  c.mccann@auckland.ac.nz
Sue Crengle  (09) 923 7866  s.crengle@auckland.ac.nz
Linda Worrall  l.worrall@uq.edu.au

I. The experiences of Māori with aphasia and their whānau

Version three: 18 July 2011
Kia ora,

You are invited to take part in a research study finding out about the experiences of Māori with aphasia (language disorder), and their whānau.

**Do I have to take part in this study?**

No. You can choose if you want to take part in the study. If you decide not to take part, this will not affect any therapy you are receiving.

If you do take part, you can change your mind at any time. You do not have to give a reason.

This information sheet will give you information about the study. It may help you decide if you would like to take part. Please tell us if you have any questions.

**Can I think about it for a while?**

Yes. You can take some time to think about whether you want to take part in this study. You can talk about it with someone from your whānau or a friend.

**Why are we doing this study?**

We are trying to find out about the experiences of Māori with aphasia, and their whānau.

Speech language therapists know a little about how aphasia affects people’s lives. We do not know the ways that aphasia affects Māori whānau. We want to find out what it is like for Māori whānau living with aphasia.

**What is aphasia?**

Aphasia is usually caused by a stroke. Aphasia affects a person’s ability to communicate with others. If you have aphasia, you may find it hard to:

- Talk
- Understand others when they speak
- Read
- Write
- Use numbers and do calculations

2. The experiences of Māori with aphasia and their whānau

Version three: 18 July 2011
Who will be in this study?

This study is for Māori with aphasia, and their whānau. We are looking for people who:

- are aged over 18
- have aphasia caused by a stroke
- have had aphasia for at least six months
- are able to participate in an interview, with support if required
- are living in the community
- have whānau (not necessarily Māori) who will participate in interviews

About ten people with aphasia, and their whānau, will be in this study.

If you decide to take part in this study you can choose who you would like to include as your whānau. Your whānau do not have to be Māori.

What will I have to do?

A kōrero (interview) will be arranged with you and your whānau to talk about living with aphasia.

There will be some questions for you and some questions for your whānau. You and your whānau can choose whether you want to kōrero separately or together.

A few weeks later, another kōrero will be arranged to check that what we talked about the first time has been understood.

Each interview will take approximately 45 to 90 minutes.

You do not have to answer all the questions.

You can speak Te Reo if you want to. We can use an interpreter.

I would like to record the interviews (video or tape recorder).
**Where will the interviews happen?**

The interview can take place where you choose. It might be:

- Your home
- Somewhere in the community
- The University of Auckland

You do not need any money to take part in this study. If it costs you to get to the interview, I will reimburse your local travel.

**What will happen with the information that I provide?**

What you say in the interviews is confidential.

If you do not want people to know that you participated in the study we will not tell anyone. If you are happy for people to know that you participated in the study, we will write your name in the acknowledgements section.

The rangahau whānau (research advisory group) will approve any research findings before they are presented or published.

Your information will be kept in a locked cabinet. The recordings of your interviews will be stored on a computer with a password.

You can have a copy of the recording of your interviews, if you want.

The recordings will be deleted when the study is finished.

All the information will be destroyed after 10 years.

You can have a summary of the results. These will be available in 2013.

**Can I stop taking part in the study?**

You can stop at any time during the interviews.

Even if you have finished all the interviews, you can still withdraw from the study. This needs to happen before data analysis finishes (about June 2011).
What are the benefits of taking part in the study?

Benefits for You:
You and your whānau might find it helpful to talk about your experiences with aphasia.
You will receive a small koha.

Benefits for Others:
You will help speech language therapists learn more about what it is like to be Māori living with aphasia.
The interviews are not speech therapy.
This study will not help your communication.

What are the risks of taking part in the study?
There should not be any risk to you.
You may find the interviews tiring.
This is common after a stroke.
If you are tired, we can take a break, or, we can finish the interview another day.

Second study
We are planning a second study.
There will be a kōrero about how you think speech language therapists could help Māori with aphasia and their whānau.
If you would like to take part in the second study please tick “yes” on the consent form.
You can change your mind at any time.
Where can I find out more information?

If you want more information please contact Karen McLellan or Sue Crengle. Someone from your whānau or a friend can do this for you if you want.

Your rights as a participant

If you have any queries or concerns about your rights as a participant in this study, you can contact an independent health and disability advocate:

📞 0800 555 050

Fax 📭 0800 2787 7678

💻 advocacy@hddc.org.nz

Ethics Approval

This study has received ethical approval from the Northern Y Regional Ethics Committee.

6. The experiences of Māori with aphasia and their whānau

Version three: 18 July 2011
Appendix D: Consent form, person with aphasia

Consent Form – person with aphasia

**Project Title:** The experiences of Māori with aphasia (language disorder) and their whānau

**Researcher:** Karen McLellan  
**Supervisors:** Dr Clare McCann, Dr Sue Crengle, Prof Linda Worrall

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<th>Translation</th>
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<td>English</td>
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<td>Deaf</td>
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<td>No</td>
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<td>Māori</td>
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<td>Kao</td>
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<td>Cook Island Māori</td>
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<td>Tongan</td>
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This study has received ethical approval from the Northern Y Regional Ethics Committee.

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1. The experiences of Māori with aphasia and their whānau  
Version three: 18 July 2011
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<td>I know I will not receive extra therapy as part of the study</td>
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<tr>
<td>I would like a <strong>summary</strong> of the results of the study</td>
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2. The experiences of Māori with aphasia and their whānau

Version three: 18 July 2011
I would like Karen to contact me about taking part in another study about Māori and aphasia

I know that I can say no to taking part in the other study

I would like these people from my whānau to take part in this study if they can:

I ____________________________ consent to take part in this study

Date: ____________________________

Signature: ____________________________

Full names of researchers: Karen McLellan, Dr Clare McCann,
Dr Sue Crengle, Prof Linda Worrall

Contact phone number for researchers:
Karen McLellan (09) 923 4930 or 027 3888841
Dr Sue Crengle (09) 923 7866
Dr Clare McCann (09) 923 5221

Project explained by: ____________________________

Project role: ____________________________

Signature: ____________________________

Date: ____________________________

3. The experiences of Māori with aphasia and their whānau

Version three: 18 July 2011
Appendix E: Consent form, whānau members

Consent Form – whānau member

Project Title: The experiences of Māori with aphasia (language disorder) and their whānau

Researcher: Karen McLellan

Supervisors: Dr Clare McCann Dr Sue Crengle Prof Linda Worrall

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1. The experiences of Māori with aphasia and their whānau

Version three: 18 July 2011
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<tr>
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</table>
I ___________________________ consent to take part in this study

Whānau of ___________________________

Date: ___________________________

Signature: _________________________

Full names of researchers: Karen McLellan, Dr Clare McCann,
Dr Sue Crengle, Prof Linda Worrall

Contact phone number for researchers:
Karen McLellan (09) 923 4930 or 027 3888841
Dr Sue Crengle (09) 923 7866
Dr Clare McCann (09) 923 5221

Project explained by: _________________________

Project role: ___________________________

Signature: ___________________________

Date: ___________________________
Appendix F: Interview guide, people with aphasia and whānau members

Interview Guide

The semi-structured interview will be customised to each individual situation. The questions below will simply serve as prompts to encourage the participant and whānau to tell their story and will be asked only as and when appropriate.

The interviews will aim to gather information regarding the participants’ experiences of their/their whānau member’s communication disorder, its impact on their life, functioning and role in their whānau, exploration of areas of life that are important to the participant and their whānau, and anything else the participant and/or their whānau feel is important to include.

Questions
1. Tell me about the stroke
Prompt: when did it happen?

2. How has your whānau’s communication changed since the stroke?
Prompts: Specifically – person with aphasia’s understanding, speaking, reading, writing
More broadly – changes in communication for the whānau as a whole

3. How have the communication changes affected you and your whānau?
Prompts: family, relationships, health, roles in family and community, spirituality, activities

4. Has anything else changed since the stroke?
Prompts: family, relationships, health, roles in family and community, spirituality, activities

5. How have these changes affected you and your whānau?

6. Is there anything else you would like to add?

At this point make sure the following information has been provided: iwi, how long ago the stroke was; how old the person with aphasia was at the time; the relationships of the whānau members to the person with aphasia. Discuss a pseudonym to be used when referring to the person with aphasia in the write-up.
Appendix G: Confidentiality agreement, interviews with people with aphasia and whānau members

TRANSCRIBER CONFIDENTIALITY AGREEMENT

THIS FORM WILL BE HELD FOR A PERIOD OF 10 YEARS

Project Title: The experiences of Maori with aphasia (language disorder) and their whānau

Researcher: Karen McLellan

Supervisors: Dr Clare McCann, Dr Sue Crengle, Prof Linda Worrall

Transcriber:

I have been given and have understood an explanation of my role in this research project. I have been given the opportunity to ask any questions and these have been answered satisfactorily.

I understand that the participants have all voluntarily given their consent to participate in this research project on the understanding that their privacy will be respected and their identities will not be revealed to anyone.

I agree to respect the participants’ privacy and to not divulge any of the information I obtain to anyone other than the researcher or the supervising staff.

Name: ______________________________

Signature: ___________________________

Date: _______________________________

This study has received ethical approval from the Northern Y Regional Ethics Committee
Appendix H: University of Auckland Human Participants Ethics Committee approval, SLT interviews

Office of the Vice-Chancellor
Research Integrity Unit
The University of Auckland
Private Bag 92019
Auckland, New Zealand
Level 10, 49 Symonds Street
Telephone: 64 9 373 7599
Extension: 87830 / 83761
Facsimile: 64 9 373 7432

UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE

17-Dec-2012

MEMORANDUM TO:

Clare McCann
Psychology

Re: Application for Ethics Approval (Our Ref. 8790)

The Committee considered your application for ethics approval for your project entitled What are the barriers and facilitators for SLTs providing an accessible and culturally appropriate service for Māori with aphasia and their whānau?

Ethics approval was given for a period of three years with the following comment(s):

The Committee would like to make the following comments in relation to this application, which they note has been well-written.

1. The starting date needs to be changed from December 1. The starting date for data analysis in the PIS and CF will possibly need to be changed as well.
2. Spell out “SLT” in the title of the proposal (I note this was done on the PIS and CF).
3. CF: It is suggested that you ask participants for their email address or mailing address if they want a copy of their recording/transcript or if they want a summary of the results.
4. In the summary sheet of the results of the earlier study, can you modify the diagram to indicate which pairs of themes are grouped together in dyads? Also, spell out PWA.
5. Questions for SLTs: It is not clear what the difference between the 4th and 6th bullet points is. Is the 4th about things that currently exist and the 6th about things that do not, but should?

The expiry date for this approval is 12-Dec-2015.

If the project changes significantly you are required to resubmit a new application to UAHPEC for further consideration.
In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals if you wish to do so. Contact should be made through the UAHPEC ethics administrators at humanethics@auckland.ac.nz in the first instance.

All communication with the UAHPEC regarding this application should include this reference number: 8790.

(This is a computer generated letter. No signature required.)

Secretary
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Psychology
Miss Karen McLellan
Dr Suzanne Crengle

Additional information:

1. Should you need to make any changes to the project, write to the Committee giving full details including revised documentation.

2. Should you require an extension, write to the Committee before the expiry date giving full details along with revised documentation. An extension can be granted for up to three years, after which time you must make a new application.

3. At the end of three years, or if the project is completed before the expiry, you are requested to advise the Committee of its completion.

4. Do not forget to fill in the 'approval wording' on the Participant Information Sheets and Consent Forms, giving the dates of approval and the reference number, before you send them out to your participants.

5. Send a copy of this approval letter to the Manager - Funding Processes, Research Office if you have obtained funding other than from UniServices. For UniServices contract, send a copy of the approval letter to: Contract Manager, UniServices.

6. Please note that the Committee may from time to time conduct audits of approved projects to ensure that the research has been carried out according to the approval that was given.
Appendix I: Participant information sheet, SLT interviews

**PARTICIPANT INFORMATION SHEET** (Speech-language therapists and professional leaders)

**Project title:** What are the experiences of speech-language therapists (SLTs) providing an accessible and culturally appropriate service for Māori with aphasia and their whānau?

**Names of Researchers:**
Karen McLellan: speech-language therapist and PhD student, The University of Auckland
Dr Clare McCann: lecturer, School of Psychology (Speech Science) The University of Auckland, Co-supervisor.
Prof Linda Worrall: Co-director Communication Disability Centre, The University of Queensland, Co-supervisor.

**Project description and invitation**
You are invited to be part of a research project about SLTs providing an accessible and culturally appropriate service for Māori with aphasia and their whānau. This project follows on from another study entitled “The experiences of Māori with aphasia and their whānau”. This new project aims to explore the findings of the earlier study about the experiences of Māori with aphasia and their whānau.

You have been invited to participate in this research project because you showed interest in the project about the experiences of Māori with aphasia and their whānau, either by recommending participants for the study or by discussing the findings with the researchers.

**Project procedure**
Participating in this study is voluntary (your choice). If you agree to participate in this study you will be asked to participate in one interview, approximately one hour long. The interview will be audio recorded and the recording will be transcribed by a third party. The third party will sign a confidentiality form. You will be offered a copy of the audio recording of your interview and you will be offered the opportunity to check the transcript of your interview. If you opt to check your transcript you will be given 10 working days in which to request any changes to your transcript. After this time we will presume that you are happy with the transcript and will proceed with analysis.

Participation in this study is unlikely to cause you any harm. Participation in this study will not directly benefit you.

**Data storage/retention/destruction/future use**
Consent forms will be stored at The University of Auckland for a period of six years. Consent forms will be stored separately from other data so that names of participants cannot be linked to interview transcripts.
Interviews will be transcribed by a third party who has signed a confidentiality agreement. Audio recordings will be stored on a password-protected computer until all analysis and writing is complete, at which point they will be erased. Electronic data (including electronic copies of transcripts) will be stored on a password-protected computer during the period of analysis and then transferred to a memory stick and stored in a locked cabinet for six years. After six years paper documents will be shredded and electronic data erased.

**Right to withdraw from participation**
If you decide to participate you have the right to withdraw from participation at any time. You may withdraw your data up to the point where data analysis begins (28 February 2013).

**Anonymity and confidentiality**
Participation in this study is confidential. Every attempt will be made to ensure participants are not identified. The findings of this research will be presented at conferences and published in academic journals, but participants will not be identified. This project forms part of a doctoral thesis, which will be available through The University of Auckland library.

**Summary of findings of the study**
A summary of the findings of the study will be made available to participants once the project is completed. Please indicate on the consent form if you wish to receive a copy of this document.

If you have any questions or concerns about this study please contact:

**Researcher:**
Karen McLellan  
k.mclellan@auckland.ac.nz  
Speech Science (Psychology)  
The University of Auckland Tamaki Campus  
Private Bag 92019  
Auckland 1142  
Ph: 09 923 4930

**Supervisor:**
Dr Clare McCann  
c.mccann@auckland.ac.nz  
Speech Science (Psychology)  
The University of Auckland Tamaki Campus  
Private Bag 92019  
Auckland 1142  
Ph: 09 923 5221

**Head of School:**
Ass Prof Doug Elliffe  
School of Psychology  
The University of Auckland  
East Wing Human Sciences Building  
Level 6, Room 2011-E-661  
10 Symonds St  
Auckland 1010  
Ph: 09 923 5262

For any queries regarding ethical concerns you may contact:
The Chair, The University of Auckland Human Participants Ethics Committee  
The University of Auckland, Research Office  
Private Bag 92019  
Auckland 1142  
Telephone 09 373-7599 extn. 87830/83761, Email: humanethics@auckland.ac.nz

Approved by The University of Auckland Human Participants Ethics Committee on 17 December 2012 for three (3) years. Reference number 8790.
Appendix J: Consent form, SLT interviews

CONSENT FORM (Speech-language therapists and professional leaders)

THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

Project title: What are the experiences of speech-language therapists (SLTs) providing an accessible and culturally appropriate service for Māori with aphasia and their whānau?

Names of Researchers: Karen McLellan, Dr Clare McCann, Prof Linda Worrall

- I have read the Participant Information Sheet, have understood the nature of the research and why I have been invited to participate. I have had the opportunity to ask questions and have them answered to my satisfaction.
- I agree to take part in this research.
- I understand that I am free to withdraw my participation at any time, and to withdraw any data traceable to me up to 28 February 2013.
- I understand that data will be kept for 6 years, after which they will be destroyed.
- I understand that participation in this study is confidential and every attempt will be made to ensure participants are not identified in any reports.
- I agree to be audio recorded.
- I wish / do not wish to receive a copy of my audio recording.
- I understand that a third party who has signed a confidentiality agreement will transcribe the recordings.
- I wish / do not wish to receive a copy of my interview transcript.
- I understand that if I opt to receive a copy of my interview transcript I will have 10 working days to make any changes, after which time analysis on the transcript will begin.
- I wish / do not wish to receive the summary of findings of the study.

If you would like to receive a summary of findings, please include your email address here

Name __________________________ Signature __________________________ Date ______________

Approved by The University of Auckland Human Participants Ethics Committee on 17 December 2012 for three (3) years. Reference number 8790.
Appendix K: Interview guide, SLT interviews

### Questions for speech-language therapy professional leaders

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<td>Where trained</td>
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<td>Year of graduation</td>
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<td>Years of NZ experience</td>
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<td>Years of overseas experience</td>
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<td>Other countries worked in</td>
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- Can you describe your experiences of managing speech-language therapy services for Māori with aphasia and their whānau?
- Can you describe what an accessible and culturally appropriate service for Māori with aphasia might look like?
- Can you describe any challenges to providing an accessible and culturally appropriate service?
- What helps you provide an accessible and culturally appropriate service?
- What limits your ability to provide an accessible and culturally appropriate service?
- Can you describe anything that may help you to provide an accessible and culturally appropriate service in future?

### Questions for speech-language therapists

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<td>Where trained</td>
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<td>Years of NZ experience</td>
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<td>Years of overseas experience</td>
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<td>Other countries worked in</td>
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</tbody>
</table>

- Can you describe your experiences of providing speech-language therapy services for Māori with aphasia and their whānau?
- Can you describe what an accessible and culturally appropriate service for Māori with aphasia might look like?
- Can you describe any challenges to providing an accessible and culturally appropriate service?
- What helps you provide an accessible and culturally appropriate service?
- What limits your ability to provide an accessible and culturally appropriate service?
- Can you describe anything that may help you to provide an accessible and culturally appropriate service in future?
Appendix L: Confidentiality agreement, SLT interviews

TRANSCRIBER CONFIDENTIALITY AGREEMENT

Project Title: What are the issues for speech-language therapists (SLTs) providing an accessible and culturally appropriate service for Māori with aphasia and their whānau?

Researcher: Karen McLellan

Supervisors: Dr Clare McCann, Prof Linda Worrall

Transcriber:

I agree to transcribe the audio recordings for the above research project. I understand that the information contained within them is confidential and must not be disclosed to, or discussed with, anyone other than the researcher and her supervisors.

Name: __________________________

Signature: ________________________

Date: ____________________________