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The complexities of designing therapy for Māori living with stroke-related communication disorders

Karen M Brewer, Clare M McCann, Matire LN Harwood

ABSTRACT

Stroke-related communication disorders can have a substantial impact on Māori whānau (extended family). Timely and appropriate speech-language therapy is required, but there are many challenges in providing this. In this article we discuss the need for a kaupapa Māori approach to speech-language therapy that is designed by Māori for Māori, and undertaken in a Māori way. We report the results of a literature review that revealed a small but significant body of literature describing Māori experiences of stroke, aphasia and speech-language therapy, and evidence that a Māori-specific therapy programme can improve outcomes for people with stroke. We then consider the social and political context that impacts the design and delivery of such an approach. Informed by the literature, we propose a hierarchy of skill and resource acquisition for speech-language therapists, in which they learn why to be culturally safe, how to be culturally safe, and how to interact before creating resources to build relationships, resources for education and for therapy. The creation of a kaupapa Māori speech-language therapy approach should bring together people with stroke, whānau members and service providers to create therapy that crosses sectors and disciplines and acknowledges the wider social and political context.

Approximately 67% of people admitted to hospital with stroke will have a communication impairment,¹ including motor speech disorders (dysarthria and apraxia of speech), language disorders (aphasia) and cognitive communication disorders. International research shows that, compared to other stroke survivors, people with stroke-related communication disorders have lower health-related quality of life,² are less likely to return to work,³ and more likely to suffer from depression.⁴ Stroke-related communication disorders can reduce social participation and leisure activities^{5,6} and negatively impact family relationships.^{7,8}

Given the effect of communication disorders on family and social life, and the connection between language and culture, it is likely that stroke-related communication disorders are culturally-determined. There is a small but growing body of research about bilingual speakers with aphasia,^{9,10} but almost none on bilingual people with motor speech disorders caused by stroke. Another significant gap in the literature

surrounds cultural factors, which play a vital but under-recognised role in aphasia.¹¹ Integrated with linguistic and cultural factors, experiences of aphasia are also shaped by social, political, historical, and economic processes.¹² These are areas in which many indigenous peoples have significant, and often negative, experiences. It follows that indigenous peoples might have unique experiences of stroke-related communication disorders and, consequently, unique needs for speech-language therapy.

In this article we focus on Māori experiences of stroke-related communication disorders and suggest direction for a suitable speech-language therapy approach for this population. In doing so we employ kaupapa Māori theory, “a foundation for theory and research [that] has grown out of Māori struggles for tino rangatiratanga and mana motuhake”.¹³ Tino rangatiratanga and mana motuhake can both be translated as self-determination, sovereignty, autonomy or self-government. Kaupapa Māori theory is cultural and political.¹³ It is transfor-

mative (aims to make a positive change for Māori) and decolonising¹⁴ (this includes working within a Māori world view to understand and use research for Māori purposes¹⁵). These concepts are all essential in the development of a speech-language therapy approach for Māori, one which could be called “kaupapa Māori”.

In 2011, McLellan, McCann and Worrall¹⁶ completed a structured review of the literature, asking whether Māori with aphasia and their whānau were being included in research and what, if any, specific outcomes or concerns had been reported. This search revealed no published literature involving Māori participants stated to have aphasia. We repeated the search in July 2015, seeking work dating from 2011. The aim was to ascertain the extent of the literature now available and gain direction for future research on this topic. This search revealed six articles,¹⁶⁻²¹ one unpublished doctoral thesis²² and one book chapter.²³ In addition, it uncovered an article²⁴ showing lower levels of stroke awareness and knowledge of how to treat stroke in Māori members of the New Zealand public compared to New Zealand Europeans. Several recent articles about aphasia in Aboriginal communities in Australia^{25,26} were also found. In addition, we are aware of a second unpublished doctoral thesis.²⁷

To be of relevance to more people with stroke, we widened the scope to include all stroke-related communication disorders, and repeated the literature search using the terms ‘Māori’ AND ‘dysarthria’, ‘Māori’ AND ‘apraxia’ and ‘Māori’ AND ‘right hemisphere language’, with no limits on dates. No articles relevant to Māori with stroke were revealed for any of the terms. Having found no articles about communications disorders other than aphasia, we proceeded to analyse the aphasia literature. We recognise that the findings do not necessarily extend to all communication disorders, but expect that many issues will be similar.

While it is pleasing to see an increase in publications on this topic, most of the Māori aphasia articles were by our research team.^{16-20,22} These cover the methodologies used in the programme of research,¹⁸ insight into the experiences of Māori with aphasia and their whānau members,¹⁹ Māori expe-

riences of speech-language therapy,¹⁷ and speech-language therapists’ (SLTs) experiences working with Māori whānau.²⁰ In Harwood’s thesis,²⁷ whānau with stroke were interviewed about all aspects of their stroke, goals, rehabilitation and recovery. Participants expressed a need for more information about speech-language therapy and support from SLTs. Neuropsychology research²³ has highlighted the difficulties in undertaking formal assessment with Māori with aphasia when there are no culturally-appropriate assessment tools available. Finally, a randomised controlled trial with Māori and Pacific people (some of whom had communication disorders) showed that participation in a self-directed rehabilitation programme significantly improved health-related quality of life and reduced dependence and carer strain.²¹

Between all of these articles, Māori experiences of aphasia and the challenges faced by clinicians in this field are now well described. However, only one of the articles²¹ offers a therapy approach, and this is generic stroke rehabilitation that may not be suitable for people with communication disorders. While revealing a lack of speech-language therapy intervention studies, the literature provides a solid foundation on which therapy could be built, and evidence that stroke rehabilitation outcomes can be improved with the provision of a suitable intervention.²¹ The literature shows that whānau with stroke are seeking a culturally-safe therapy service, in which they feel comfortable, respected and able to receive care as Māori.^{17,27} Equally, SLTs have expressed a desire to practise in a culturally-safe manner.²⁰ Whānau are seeking guidance from SLTs so they can take care of their own rehabilitation.¹⁷ Non-Māori SLTs require guidance from Māori colleagues to work successfully with Māori whānau.²⁰ Whānau with aphasia report frustrations arising from having insufficient information about their communication disorder, speech-language therapy, and how to support rehabilitation.¹⁷ At the same time, SLTs recognise a need for specific information and education about how to work with Māori whānau.²⁰ Linked to the desire for information, both whānau and clinicians have identified a need for therapy resources

and settings that reflect the world views and identities of whānau.^{17,20,23}

In summarising this literature, it became abundantly clear that post-stroke therapy resources are desired by Māori, Māori whānau and clinicians. However, the development of kaupapa Māori speech-language therapy for stroke-related communication disorders is not straightforward. The impact of the social, political, historical, and economic context¹² means that the availability of a Māori therapy resource would not address all the issues associated with speech-language therapy provision for Māori. The therapy would be for whānau who have their own personal context shaped by culture, colonisation and collective experience. It would be undertaken by SLTs who have a personal culture as well as the professional culture of their discipline, and are working for a health organisation that is within a health system. We will address these complexities and suggest a solution in the remainder of this article.

Social and political context

The Treaty of Waitangi is the fundamental political context for Māori health, and therefore the development of a kaupapa Māori therapy approach for stroke-related communication disorders. Under Article Two of the Treaty, Māori have the right to exercise tino rangatiratanga. Article Three entitles Māori to “a fair share of society’s benefits” of good health.²⁸ Current inequities in health status between Māori and non-Māori²⁹ demonstrate that Article Three is not yet being fulfilled. The equity of outcomes promised in Article Three is more likely to be achieved if Article Two is fulfilled and Māori are able to exercise tino rangatiratanga over resources and service delivery.

*He Korowai Oranga: Māori Health Strategy*³⁰ has the overarching goal of “pae ora” (healthy futures). It includes four “pathways for action” that provide many concepts important for kaupapa Māori speech-language therapy. The first pathway focuses on community development, capacity building, and removal of barriers so that Māori communities and individuals, including those with disabilities, are able to manage their own wellbeing and long-term

health outcomes. The second recognises that, to ensure the services are “appropriate and effective for Māori”, Māori must be involved in decision-making and service delivery. The third acknowledges that most Māori receive care from mainstream services, and these services need to work hard to reduce health inequalities and achieve good outcomes for Māori. The fourth states that service provision should be structured to provide “seamless delivery of care” that meets whānau needs rather than providers’ needs.

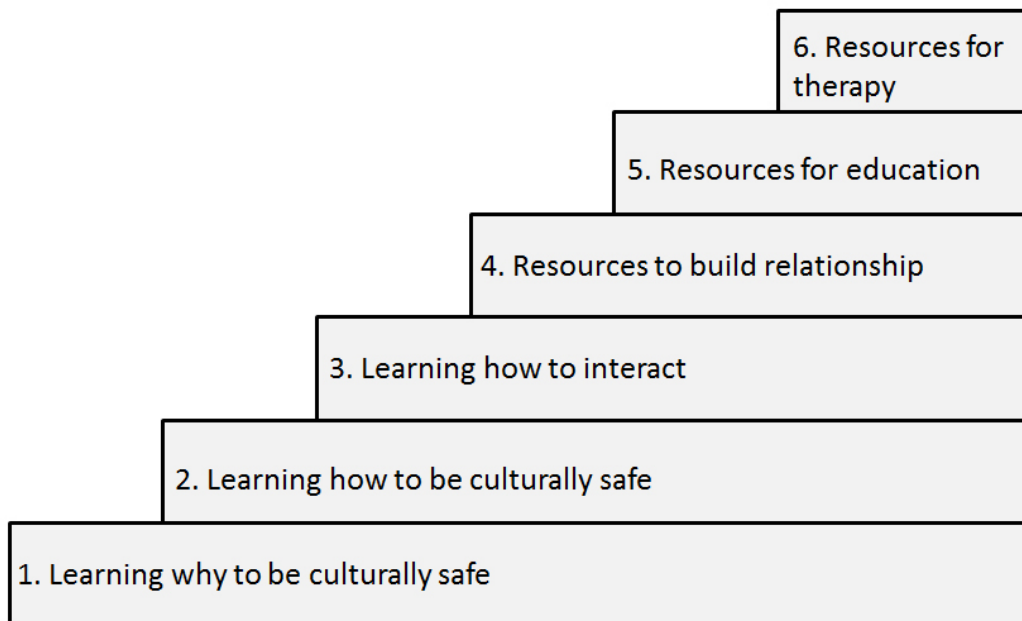
Whānau Ora is the New Zealand government’s current approach to health and social service delivery. The Taskforce on Whānau Centred Initiatives³¹ identified the following key characteristics of Whānau Ora. These could be taken as guidelines for the development of a speech-language therapy approach. Whānau Ora:

1. Is about group (ie, whānau) wellbeing
2. Is about self-determination
3. Values bidirectional intergenerational exchanges
4. Has a strong cultural dimension
5. Is concerned with the ways whānau interact with wider society
6. Transcends sectors.

These documents provide guidance as well as challenges for the development of a kaupapa Māori therapy approach for stroke-related communication disorders. They clearly demonstrate that to be successful, and reduce inequities, the therapy must have a strong cultural dimension and be led, developed, delivered, and owned by Māori. It should provide Māori communities and individuals with tools to work towards self-determined goals to manage their own wellbeing and long-term health outcomes. It should seek to improve intergenerational communication within the whānau, and address the barriers and communication needs of whānau when interacting with and contributing to wider society. The therapy must not sit solely with the discipline of speech-language therapy, but facilitate working across disciplines to benefit whānau.

Striving to be decolonising, kaupapa Māori speech-language therapy does not need to have a relationship with He Korowai Oranga, Whānau Ora or any other

Figure 1: Poutama showing proposed hierarchy of SLT skill and resource acquisition.



government documents. However, because speech-language therapy services for adults are only provided within the ‘mainstream’ public health system, they are delivered by clinicians who have an obligation to follow government health policy. The challenge is to provide kaupapa Māori therapy for stroke-related communication disorders that can be delivered by non-Māori therapists within a non-Māori system. Questions remain as to whether this is even possible.

A hierarchy of skill and resource acquisition

Considering the social and political context, and having acknowledged that a therapy resource alone is unlikely to improve therapy outcomes, we propose an approach in which the SLTs cultural safety and clinical skills are developed before kaupapa Māori resources are provided. The proposed approach is illustrated by the poutama (stepped pattern) in Figure 1.

1. Learning why to be culturally safe

Culturally-safe interactions begin with the SLT learning why it is important to be culturally safe. In New Zealand, the application of cultural safety is intertwined with Te Tiriti o Waitangi.³² Therefore, an

understanding of the Treaty of Waitangi and Māori status as tangata whenua is required. Cultural safety focuses on the culture of the clinician and discipline, and the clinician as the bearer of power, whether they are aware of it or not.³² The focus is not on the cultural practices of a group, but how they are perceived and treated by society.³³ Learning why to be culturally safe, therefore, involves SLTs understanding their individual cultures and that of the SLT profession. It requires an analysis of the power inherent in the position of the SLT and how this can be managed in the clinical setting. It also requires critical analysis of how Māori are perceived and treated, including knowledge of health inequities and social determinants of health.

2. Learning how to be culturally safe

Once a clinician understands why to be culturally safe, they can learn how to be culturally safe. Learning how to be culturally safe involves developing a culturally-safe mind-set in which the clinician recognises and tries to eliminate power differences.³² Whānau have expressed a desire for guidance from SLTs so they can take care of their own rehabilitation.¹⁷ This is an example of tino rangatiratanga, or self-determination,

which is part of culturally-safe practice. For true whānau tino rangatiratanga, the SLT and whānau must work in partnership. Working in this way may require changes in models of service delivery or scope of practice, changes the speech-language therapy profession may not be ready to make.²⁰ Improving cultural safety in speech-language therapy is not straightforward. Cultural safety aims to change individual attitudes, but if social structures are not redesigned, changing individual attitudes will make minimal difference.³³ Therefore, it is difficult for clinicians to provide a culturally-safe service for Māori when they work within systems that are not compatible with Māori ways of being.

3. Learning how to interact

Once clinicians have acquired a culturally safe attitude they can learn how to interact in a way that demonstrates that attitude to Māori patients and whānau. Learning how to interact is fundamentally different to learning how to be culturally safe. Addressing power differences is essential for culturally-safe practice.³² However, clinicians can learn how to interact without acknowledging power, such as the techniques taught in transcultural nursing.³⁴ If a clinician learns how to interact without learning how to be culturally safe, Māori may perceive his or her actions as patronising or hypocritical.

4. Resources to build relationship

Once a clinician understands why and how to build a relationship with Māori whānau, they can be guided to develop resources which can be used to help build that relationship. This might include processes for interacting with Māori patients and whānau (eg, the Hui process³⁵), building relationships with Māori health colleagues who provide cultural support, or creating physical resources such as photo books to use when building a relationship with patients with language disorders.

5. Resources for education

Resources for education will enable the SLT to provide guidance for the whānau about the nature of the stroke and communication disorder, the role of the SLT and ways for whānau to assist rehabilitation, needs which have been identified by whānau living with aphasia.¹⁷ There are many challenges involved in providing information for people with stroke and whānau. It needs to be provided by the right people, at the right time, and in the right format.³⁶ Provision of health information is closely intertwined with health literacy and the information needs to be provided in a way that is accessible.³⁷ Kaupapa Māori directs that, as well as being at an accessible reading level, health information presented to Māori needs to be decolonising; not marginalising Māori or taking a deficit approach. In addition, health information should privilege mātauranga Māori (traditional Māori knowledge).

6. Resources for therapy

When all of this has been achieved the focus can shift to the final element, the provision of resources for use in speech-language therapy (eg, communication assessments, picture cards and reading passages). While it is tempting to begin at this point, therapy is not so much about the resources used, but the relational ability and cultural safety of the person using them. If kaupapa Māori resources are provided to an SLT who has not mastered the earlier steps, they are unlikely to be beneficial, and could even be harmful.

There are a few factors to consider when developing Māori therapy materials. Māori should have control over the design, content, and method of delivery, and the therapy should work towards self-determined goals.^{30,31} Māori resources need to be created by Māori, for Māori, using mātauranga Māori. Given that the application of mātauranga Māori varies between Māori groups,³⁸ a true kaupapa Māori resource can never be pan-Māori. It is necessary to use mātauranga-ā-iwi³⁸ to create iwi or hapū specific resources. The magnitude

of such a task is immediately apparent. In the absence of any Māori speech-language therapy resources, and considering the time required to create them, in the short-term, a generic Māori resource might be better than no Māori resource at all. This could be created in a way that allows it to be tailored for individual iwi or hapū. Alternatively, rather than creating any resources, it might be preferable to provide SLTs with cultural safety education, cultural support and guidelines for how to use existing resources (whānau photos, artefacts, magazines, etc) in therapy. This way the resources would always be suitable for the whānau because they belong to the whānau. This approach would require a higher skill level from clinicians, increasing the likelihood of resources being utilised correctly.

Conclusion

In preparing this article we repeated and extended the literature search under-

taken in 2011.¹⁶ This revealed that in the intervening years, a small but significant body of literature has developed, describing experiences of stroke, aphasia and speech-language therapy. There is evidence that Māori-specific interventions can improve outcomes.²¹ Gaps remain in the areas of communication disorders other than aphasia, and specific speech-language therapy approaches and resources. The design and delivery of a speech-language therapy approach is impacted by the social and political context. While this context can be challenging, He Korowai Oranga and Whānau Ora already provide many of the necessary guidelines and outcomes to support the process. Guided by the existing literature, and working with whānau with stroke-related communication disorders, SLTs, and Māori health staff, we are now moving forward with the development of a kaupapa Māori therapy for stroke-related communication disorders.

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