THE EXPERIENCE OF WHANAU CARING FOR MEMBERS DISABLED FROM THE EFFECTS OF STROKE

A thesis presented in partial fulfilment of
the requirements for the degree of

MASTER OF PHILOSOPHY

Massey University

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This thesis explores the experience of whanau caring for members disabled from the effects of stroke. The decision to undertake this study arose from my experience in rehabilitation nursing where I observed Maori accepting the responsibility for the care of their whanau member following a stroke with little assistance from existing rehabilitation and community based services. I wanted to understand why this was so, from the perspectives of the whanau. A review of epidemiological data demonstrated the negative disparity in the incidence of stroke in Maori when compared with non-Maori. Further review of the literature specifically related to Maori health issues revealed that whilst there was acknowledgement of the importance of whanau, kaumatua and kuia to Maori as a society, there was little that dealt with disability issues and stroke in particular. Where issues related to the provision of, and access to, health and disability services had been noted, little appears to have been accomplished. A descriptive qualitative research study was undertaken in the Taranaki region with support of the eight Taranaki iwi. Seven whanau focus groups interviews and three key informant interviews were undertaken. From analysis of the data a descriptive account of the whanau experience of onset of the stroke event, hospitalisation and service delivery following discharge of their whanau member is provided. The impact on the whanau of their ongoing provision of care with limited service provision from health and disability services is explored. On the basis of this analysis a number of recommendations are made. The key recommendation is that there needs to be a review of current rehabilitation service provision in Taranaki. From such a review it is hoped that changes will be implemented that will enable service provision to be more beneficial, accessible and acceptable to Taranaki Maori.
HE MIHI

Tena kouto Rou Rangitira ma

I acknowledge the people gathered

Ka mihi hoki ki Nga Mana Ki nga Reo kua tae mai nei

With their mana and reo intact

Ki nga Tupuna kua wehe atu

To the ancestors that have departed

Haere Haere, Haere ki te po

Farewell, farewell, farewell

Ko matou nga kanohi ora

To us the living

E noho nei

Who are here today

Tena kotou tena koutou

Greetings, Greetings

Tena koutou katoa

Greetings.

My mother is Lilian from the Manawatu,
My father Timothy from Taihape.

I was born and grew up in New Plymouth living next door to Aunty Marge;
respected Kuia of the Taranaki Iwi.
My whanau have links with Ngati Ruanui forged following the returning of a sacred taonga, (a stone adze), following the death of my father who found it on his farm south of Stratford.

I trained as an Enrolled Nurse in Te Kuiti, 29 years ago and then as a Registered General and Obstetric Nurse here in New Plymouth.

I have worked in rehabilitation as an educator and resource nurse in the Waikato, and as Clinical Nurse Leader of the rehabilitation service in the Wairarapa before coming to the Western Institute of Technology at Taranaki in July of 2001 to tutor in the Bachelor of Nursing Programme.

Apart from the other courses I am responsible for delivering, I am responsible for facilitating Kawa Whakaruruhau across all three years of the Bachelor of Nursing programme. As Tauiwi, I do this in a consultative manner with Tui Ora Limited, and Kuia and Kaumatua of the eight Taranaki Iwi.

My desire in undertaking this study was to understand and then to enrich the whanau experience of stroke, with the hope that we might enable a better partnership between the traditional and non-traditional ways of caring.
ACKNOWLEDGEMENTS

In undertaking this study, as a tauwi researcher I did not appreciate the long and difficult journey that I was embarking upon.

Throughout the journey I have been constantly buoyed by the expression of whanau who wanted to tell their story for the potential benefit of future whanau experiencing the trauma and devastating effects of stroke. I acknowledge the personal commitment of the participants of those whanau groups that wanted and desired that their stories be told.

This thesis would not have been possible without the full and complete support and encouragement of Taranaki Maori:

The Maori Development Organisation, Tui Ora Limited; South Taranaki Iwi, Ngati Ruanui; the Taranaki Maori Health Forum, Te Whare Punanga Korero; Kuia, Makere Wano; Kaumatua, Matua Tony Waru and Matua Barry Whakaruru and the Maori Disabilities Advocate of the He Whakaruruhau Trust, together formed my research whanau without whom this thesis would not have been undertaken.

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I acknowledge the consent and approval of the Ministry of Health and the Waitangi Tribunal for permission to use Tables and Figures from their publications.

I am grateful to my family, Colleen and Ciaran, and my mother Lilian who found time to encourage me whilst struggling with completing her own “thesis” of life as she fought her battle with breast cancer. For their ongoing encouragement and support so that I might achieve something of worth for the benefit of Taranaki Maori, I am eternally grateful.

Tena kotou, tena kotou, tena kotou katoa.

Andrea M Corbett
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GLOSSARY

Aroha – love
Atua – gods
Aukiti – prevention factors and promotion of health
Awatea – a holistic approach to Maori development
Hapu – sub tribes of an iwi
Hauora – health in its widest interpretation
Hinengaro – the mind, thoughts and feelings
Hui – formal gathering/meeting
Io – the supreme God, the one before all others
Iwi – tribal groupings claiming descent from one waka
Karakia – prayer
Karakia tuku tuku – prayers of last rites
Kaumatu – an older, wise and respected Maori, usually male. One who knows the tikanga and whakapapa of the hapu and iwi, acknowledged by his people
Kaupapa – a theme or groundwork; rules and policy
Kawa Whakaruruhau – cultural safety
Korero – discussion
Kuia – older and wise woman
Mana ake – unique qualities of the individual
Manaakitanga – the role of the whanau of protection and nurturing
Manaakitia – the capacity to care
Marae – a physical location or area set aside for the practice of Maori customs
Matua whangai – the custom of the grandparents raising and taking care of the grandchildren
Mauri – life force
Mihi – greeting of introduction
Mirimiri – massage
Mokopuna – grandchild
Noa – a state of relaxed access. Usually follows the lifting of a tapu state
Pakeha – immigrants or descendents of immigrants from Europe

Papatuanuku – earth mother

Pupuri taonga – the guardianship role of whanau

Ranginui – sky father

Rangitiratanga – self management by Maori

Rongo – god of herbs and plants

Rongoa – the practice of traditional healing using herbs and plants

Taha Maori – an attitude, a perspective, a view or picture, a Maori way of doing something

Tamariki – a child

Tangata whenua – people of the land

Tangi – funeral

Tane – god of the forests

Tangaroa – god of the seas

Taonga – something regarded as a treasure

Tapu – a sacred state, often a safety measure

Tauiwi – non-Maori New Zealander

Tawhito – the ancient ones

Te ao Maori – the Maori world view

Te reo – the first language of Maori

Te Tiriti o Waitangi – The Treaty of Waitangi

Tikanga – the right/correct way of doing something

Tinana – the physical body

Tino rangitiratanga – self determination

Tipuna – ancestors

Tohatohatia – the capacity to share resources

Tua-atea – transcendent eternal world of the spirit

Wai – water

Wairua – the spiritual force
Whakama – embarrassment

Whare tapa wha – a model of Maori health, based upon the four supporting walls of a house

Wakamana – the enabling of whanau members

Whakatakatō tikanga – to plan for future resources

Whakapapa – genealogical knowledge; the genealogical descent of all living things from the Gods

Whakatauki -- proverb

Whanau – the family

Whangai – adoption, formal or informal

Whatumanawa – open expression of emotion

Whenua – land, placenta
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADL</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>AHB</td>
<td>Area Health Board</td>
</tr>
<tr>
<td>ARCOS</td>
<td>Auckland Regional Coronary or Stroke Study</td>
</tr>
<tr>
<td>AT&amp;R</td>
<td>Assessment, Treatment and Rehabilitation</td>
</tr>
<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
</tr>
<tr>
<td>CHE</td>
<td>Crown Health Enterprise</td>
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<tr>
<td>CVA</td>
<td>Cerebral vascular accident</td>
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<td>CVD</td>
<td>Cardio vascular disease</td>
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<tr>
<td>DALY</td>
<td>Disability Adjusted Life Years</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
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<tr>
<td>DoH</td>
<td>Department of Health</td>
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<tr>
<td>DSS</td>
<td>Disability Support Services</td>
</tr>
<tr>
<td>HFA</td>
<td>Health Funding Authority</td>
</tr>
<tr>
<td>HHS</td>
<td>Hospital and Health Service</td>
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<tr>
<td>HRC</td>
<td>Health Research Council</td>
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<tr>
<td>IHD</td>
<td>Ischaemic heart disease</td>
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<td>ILE</td>
<td>Independent Life Expectancy</td>
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<tr>
<td>MDO</td>
<td>Maori Development Organisation</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
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<tr>
<td>NASC</td>
<td>Needs Assessment Service Coordination</td>
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<tr>
<td>RHA</td>
<td>Regional Health Authority</td>
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<tr>
<td>SFNZ</td>
<td>Stroke Foundation of New Zealand</td>
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<td>TOL</td>
<td>Tui Ora Ltd.</td>
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<td>TREC</td>
<td>Taranaki Regional Ethics Committee</td>
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<td>TWPK</td>
<td>Te Whare Punanga Korero</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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