

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

**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*

**Andrea M. Corbett**

**2003**

## **ABSTRACT**

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 Taiwiwi, 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.

I am grateful to the supervisors appointed by Massey University, Professor Julie Boddy, and Maureen Holdaway. Without their critique, advice and counsel, this thesis would never have been completed.

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*

## TABLE OF CONTENTS

Abstract	.....	ii
Mihi	.....	iii
Acknowledgements	.....	v
Table of contents	.....	vi
List of tables	.....	viii
List of figures	.....	ix
Glossary	.....	x
Abbreviations	.....	xiii
Introduction to the study	.....	1
Aims of the study		
Summary of the chapters		
Chapter I: Undertaking Research With Maori	.....	6
Considerations for tauwi		
Components of Maori research		
Chapter II: Epidemiology of Stroke -- Literature Review	.....	13
Introduction		
Definition		
Risk factors		
Independent Life Expectancy		
Disability		
Incidence of stroke		
Issues of service access and service delivery		
Chapter III: Rehabilitation and Disability Support Services in the New Zealand Context	.....	29
Introduction		
Setting the scene		
1990 – 1996		
1996 to the present day		
Changes in health services delivery in Taranaki		
Current status of disability support services		
Chapter IV: Issues of Maori Health	.....	39
He Korowai Oranga – The Maori Health Strategy		
Whaia Te Whanaungatanga: Oranga Whanau		
Maori concepts of health		
He Anga Whakamana		
Maori and whanau		
Taranaki Maori – A profile		
Chapter V: Research Design and Method	.....	53
Introduction		
Focus groups and key informants		
Preparation for, and initiation of the study		
Ethical considerations		

	Whanau participant profiles	
	The interviews	
	Checking of transcripts	
	Analysis of content of transcripts	
Chapter VI:	The whanau experience of stroke.....	67
	The experience of the onset of stroke	
	The partner faces the situation	
	Staying with the whanau member in hospital	
	The whanau learns the hands on care	
	The independence of the patient	
	Preparing for discharge	
	Home visits and home assessments	
	Conclusion	
Chapter VII:	A Maori Perspective.....	91
	Introduction	
	The importance of whanau	
	Things particular to Maori	
	Respect for age and gender	
	The patience and tolerance of Maori	
	Conclusion	
Chapter VIII:	Discussion.....	105
	The whanau experience of stroke	
	Support for the whanau to care	
	Transport issues	
	The importance of whanau	
	Provision of services	
	Provision of information related to services	
	Expressed need for Maori based services	
	The interface between traditional/non-traditional methods of caring	
	Enrichment of the experience of stroke	
	Conclusion	
Appendices	.....	126
	1 The History of Pukerangiora	
	2 Proposal as submitted for Ethics Committee Approval	
	3 Study Information sheet	
	4 Consent Form – Te Reo	
	5 Consent Form – English	
	6 MUHEC Approval June 6, 2002	
	7 MUHEC Approval June 27, 2002	
	8 TREC Approval, May 2, 2002	
	9 TWPK Approval, May 1, 2002	
	10 Tui Ora Ltd Letter of Support, March 25, 2002	
Reference List	.....	153

## LIST OF TABLES

Table 1	Evaluating Research in Relationship to the Principles Arising from Te Tiriti o Waitangi.....	7
Table 2	DALY's lost by age, gender and ethnicity, 1996 .....	15
Table 3	DALY's lost by cause, group and gender, 1996 .....	16
Table 4	Conditions causing at least 10,000 DALY's, 1996 .....	17
Table 5	Taranaki Iwi numbers according to Census declarations 2001 .....	52

## LIST OF FIGURES

Figure 1	DALY's lost by cause, group and ethnicity, 1996 .....	16
Figure 2	Dependent disability prevalence by age and ethnicity, 1996-97 ....	20
Figure 3	Causes of mortality by gender, 1998 .....	22
Figure 4	Standardised mortality rates for ischaemic heart disease and stroke, 1980-98.....	22
Figure 5	DSS expenditure by service area, 2000/01 .....	38
Figure 6	Taranaki Iwi Boundaries .....	51

## 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
- Kaumatua – 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

Waiora – all encompassing health

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

Whakatakato 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

## ABBREVIATIONS

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