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**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**

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## 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 Tauwiwi, 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.*

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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.

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*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
- 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

## **INTRODUCTION TO THE STUDY**

This thesis presents the results of a study into the whanau experience of caring for a member disabled from a stroke. The study was conducted among Maori of the Taranaki region.

As a Registered Nurse, I have a strong clinical background of rehabilitation nursing practice for which I have a passion. I held the position of Clinical Resource Nurse for the Assessment, Treatment and Rehabilitation Service (AT&R) of Community Services, Waikato Hospital in the late 1990s. I moved on to a position as Clinical Nurse Leader of the AT&R Service of Wairarapa Health before finally leaving direct clinical practice to become a full time generalist tutor with the Western Institute of Technology at Taranaki in July of 2001.

My commitment to rehabilitation nursing practice was underpinned by academic study relevant to the field. I completed a Post Graduate Diploma in Health Science (Rehabilitation) from Otago University; and a Post Graduate Diploma in Health Science (Managed Care) from Auckland University.

In seeking a suitable research question for a Masters thesis within my sphere of interest, rehabilitation, I reflected on my experiences from different hospital environments and the questions that had arisen for me during that time. The issue that I kept returning to was how Maori seemed to be able to care for their whanau member affected by stroke and did it without much in the way of support services. What was it that enabled them to do so? Was there something unique about the whanau? Perhaps significantly I asked myself if the whanau just got on with the job because that was what was expected of them?

So the topic for this study evolved and I was determined to explore the whanau experience of caring for a member disabled by a stroke. The experiences I had lived during my childhood and early teens had laid a firm foundation upon which my later education and professional development allowed me to believe that I could undertake a research project in partnership with Taranaki Maori.

As a locally born New Plymouth woman I had grown up in the State housing suburb of Vogeltown. Living next door to us was the family of a respected Kuia, Marjorie Rau, of the Taranaki Iwi. My sisters and I went to school with her son and daughter. By a process of osmosis we were imbued with knowledge of tikanga Maori; issues of Maori land rights; knowledge of the events of Parihaka; and other knowledge of Maori in general and Taranaki Maori in particular. Tangi

and other ceremonial events held 'next door' became non-threatening events to learn from of the unknown side of the culture of our neighbours.

When I returned to live in New Plymouth after an absence of 30 years I was welcomed by another respected local kuia, Makere Wano. Among other responsibilities in my new position I was responsible for facilitating the implementation of cultural safety education across all three years of the Bachelor of Nursing programme. In this role I actively consulted and worked with this kuia, Makere; other leaders in Maori health service delivery, and the Maori Studies Department of the Institute to implement and deliver culturally appropriate programmes to my students. Makere introduced me to the principals of the local North Taranaki Maori Development Organisation, Tui Ora Limited.

As thoughts for my Masterate study began to firm and I was seriously considering a project for Maori, it was appropriate that I should consult with Makere Wano and Tui Ora Ltd. I appreciated that there had been concerns expressed over non-Maori undertaking research involving Maori. Over recent years there has been much debate regarding non-Maori undertaking research on Maori, the intellectual property rights of Maori, and some of the ethical considerations that arise from those considerations.

The issue was clearly stated by Jahnke and Taiapa (1999) who state that: "much of the research done on Maori in the past has proven to be of little benefit to Maori themselves, tending to emphasise negative statistics without attempting to provide the information necessary to effect positive change" (p. 61). A number of writers (Smith G.H., 1990; Te Awekotuku, 1991; Teariki & Spoonley, 1991; Smith L.T., 1992b; and Glynn & Bishop, 1995) have referred to research "on" Maori being self serving for the researcher with little of value obtained from the research for the Maori participants of the study. Many studies never involved Maori as participants or partners, but rather as mere subjects to be studied and commented upon. This is indicative of the process of colonisation of one people over another.

An analysis of the colonisation process as it occurred in Aotearoa/New Zealand and as it affected Maori shows that the "whole process of colonisation was the stripping away of mana" and that research was a "small but important part of the colonisation process because it was concerned with defining knowledge. To be colonised was to be defined by someone else and to believe it even though you are confronted daily by evidence to the contrary" (Smith, L. 1992a, p. 8).

I recognised that there was a deep-seated distrust in Maori communities over the whole process of research and not just of non-Maori researchers. This was confirmed from the experiences of Ngati Ruanui that are related later in this thesis (Chapter 5). In a cross-cultural context, as well as recognising personal beliefs and assumptions, the questions that I needed to ask myself included:-

- Who has helped define the research problem?
- For whom is the study relevant and worthy? Who says so?
- Which cultural group will be the one to gain new knowledge?
- To whom is the researcher accountable?
- Who will gain the most from this study?

(Smith, L., 1992a, p8).

From her analysis of research into the lives of Maori Linda Smith (1992a) states that:

many researchers have not only not found truth or new knowledge but have missed the point entirely and in some cases been quite guilty of drawing conclusions about Maori on the basis of information gathered that has only a tenuous relationship with how Maori society operates. (p. 9).

From my understanding of these issues it was possible as a non-Maori for me to undertake research with Maori and to develop the aims of the study in a negotiated partnership. I believed that it was necessary for local Maori to consider that the proposed study would be relevant to them, and that it would impart new knowledge to Maori. It also felt important that local Maori understood that a commitment and undertaking was given that saw Taranaki Maori directly involved and having control over the entire research process in partnership with myself. Makere Wano and Tui Ora Ltd were to be actively involved in all these processes. This partnership ensured that non-Maori could undertake research with Maori and that Maori intellectual property rights would be acknowledged and respected.

## **Aims of the study**

The aims of this study were:

- To develop an understanding of the experience of the whanau in caring for a member disabled by the effects of stroke.

- To identify any information that could lead to an enrichment of the experiences of the whanau caring for a member disabled by the effects of stroke.
- To identify any information that may enhance the partnership between traditional and non-traditional care as experienced by whanau.

## **Summary of chapters**

Chapter One explores the issues for non-Maori (tauiwi) to consider when contemplating undertaking Maori centred research. The issues considered in developing and designing this study, including the creation of a tool to be used to evaluate proposed research in relationship to Te Tiriti o Waitangi are described.

Chapter Two details the results of the literature review that was undertaken and in particular the epidemiology of stroke in Aotearoa/New Zealand today. The disparity in the incidence of stroke between Maori and non-Maori is clearly demonstrated. The literature review concludes with an examination of the effects of disability upon Maori, and a review of official documents related to health and disability services.

Chapter Three provides an account of the situation of health and disability services delivered in Aotearoa/New Zealand and Taranaki in particular today. The impact of the health reforms of the 1990s on the current delivery of health services in Taranaki is explored.

Chapter Four acknowledges that issues of Maori health have been central to Government advisors and health professionals over the years. Some recent key reports have been cited which lead into a consideration of whanau, Maori, and attitudes, values and beliefs related to life and health.

Chapter Five describes the decision to conduct a qualitative descriptive study using focus groups and key informant interviews. Following on from this Leininger's criteria for evaluating qualitative research that were used to assess the analysis that was undertaken on the data are examined.

Chapter Six presents a descriptive account of the whanau experience of caring for a member disabled by stroke as relayed to me at interview. Much of what was experienced by Maori was believed to be not a lot different than what is experienced by non-Maori in similar circumstances however the whanau had a unique descriptive experience to relate.

Chapter Seven utilises the research whanau expertise and wisdom to enable the study to draw together the many and diverse perspectives that are uniquely Maori to the whole experience of stroke upon the participants and their whanau.

Chapter Eight is a discussion of the findings of the study. The whanau experience of the event of stroke is discussed along with findings to support the secondary aims of the study. These were a possible strengthening of the interface between traditional and non-traditional methods of caring, and the possible enrichment of the experience of stroke for future whanau so affected. There were a number of issues that emerged from the study. These ranged from the importance and expectations of and by whanau through to the provision, or not, of services. A number of recommendations are made for consideration to conclude this study.

*NOTE: Throughout this thesis Maori words are given their closest possible English interpretation in the Glossary of Terms, page X..*

## CHAPTER ONE

### UNDERTAKING RESEARCH WITH MAORI

#### Considerations for tauiwi

I have referred to the debate that has been held in recent years regarding non-Maori undertaking research on, for, or with Maori, and some of the ethical dilemmas that can arise out of those considerations. It was therefore appropriate to review the published material of the New Zealand Health Research Council (HRC). The "Guidelines on Ethics in Health Research" were examined along with the "Guidelines for Researchers on Health Research Involving Maori." These were to prove invaluable as I began my journey to develop and conduct this study.

The Principles implied in Te Tiriti o Waitangi Articles Two and Three are restated in these Guidelines and underpin all considerations of developing any research study involving Maori. Article Two is interpreted as keeping Maori control over Maori resources, including people, and Article Three provided for a fair share of society's benefits to be received by Maori as of right. There can be no argument that Maori health has been a consideration within the Treaty since it was drafted in 1840, as what greater taonga can there be than good health?

For health research, Article Two results in the recognition that iwi and hapu have an authority over their peoples' involvement in research. Article Three generates an expectation for both an equivalent state of health between Maori and pakeha, and an equitable share of the benefits of any Crown expenditure.

The continuing disparities in standards of health between Maori and non-Maori produce a strong argument under Article Three for significant health research resources to be directed at resolving Maori health issues. High quality research is a key component in Maori health development, as it is essential that initiatives to resolve Maori health issues be based on a foundation of high quality information.

The Royal Commission on Social Policy (1988) recommended acceptance of three Principles that were relevant to social policy and any consideration of Te Tiriti o Waitangi. These Principles of Partnership, Protection, and Participation need to be examined to ensure the validity of any research project involving Maori.

I have used the critical review of indigenous research related to the educational sector as devised by Bishop (1998) as a guide in developing the following tool for consideration of any research project involving Maori. (Table 1).

**Table 1:** Evaluating Research in relationship to the Principles arising from Te Tiriti o Waitangi

	<b>Article 1 Partnership</b>	<b>Article 2 Protection</b>	<b>Article 3 Participation</b>
<b>Initiation</b>	Who establishes the goals, objectives and outcomes of the research?  Have local Iwi been involved in the decision-making from the outset?	Who defines what is a taonga and how it will be protected?  Have the means of consultation been identified?	Who defines what systems will be put in place to ensure equality of opportunity and outcome?  Is there equity of opportunity and outcomes in partnership with Maori?
<b>Benefits</b>	Who determines the benefits?  Have local Iwi had a say in determining the content of the research?	How will local Maori benefit from the research?	Are Maori actively involved in the research at all stages and levels?
<b>Representation</b>	Who is involved in the partnership?  Is the Maori voice evident in the planning for the research?	Who defines Maori aspirations, preferences and practices?  Is Iwi involvement evident in the audit trail?	Are Maori aspirations evident in constituting opportunities and outcomes of the research?
<b>Legitimation</b>	Does the researcher and the Maori partners in the research have authorisation from their controlling bodies? (eg: Ethics Committees & Iwi Authorities)	Has the research formal Ethics approval?  Is this clearly documented?	What authorities do the researchers have – institutional and local Iwi?  What monitoring processes are in place as the research proceeds?
<b>Accountability</b>	How is accountability demonstrated?  Who are the researchers accountable to?	How can the protection of cultural treasures be assured?	How are the outcomes to be monitored and by whom?

Adapted by A.M. Corbett, June 2002, from a table first published by R. Macpherson, (based on an earlier work by R. Bishop 1995), and presented by Macpherson at the 1998 Biennial conference of the New Zealand Educational Administration Society.

When it came to definitive study design this table was referred to often to ensure that decisions regarding the research proposal and methodology complied with the concepts and precepts of culturally appropriate and sensitive research.

## Components of Maori research

Bevan-Brown (1998) delivered a paper to Te Oru Ranguhau Maori Research and Development Conference held in July 1998 in which she identified what was termed "The Top 10 Components of Maori Research." She emphasised that all 10 components were important and needed to be considered in the context of any proposed study involving Maori. The components were stated as:

### I. The need to conduct Maori research within a Maori cultural framework.

Research conducted within a Maori cultural framework stems from a Maori world view, is based on Maori epistemology, and incorporates Maori concepts, knowledge, skills, experiences, attitudes, processes, practices, customs, reo, values and beliefs. Bevan-Brown cites Marsden and Henare (1992) in stating that: "The world view lies at the heart of the culture, touching, interacting with and strongly influencing every aspect of the culture" (Bevan-Brown, 1998, p. 231).

The whare tapa wha model of health articulated by Durie (1994), clearly outlines the encompassing holistic view of health and wellbeing for Maori. The four dimensions of taha wairua (the spiritual dimension), taha tinana (the physical dimension), taha hinengaro (the psychological dimension), and taha whanau (the family dimension) are all interrelated and intertwined in such a way that one cannot be considered without considering the other dimensions. Good health for Maori is dependent upon the balance of these dimensions. This model is but one of a number of models of Maori health that integrate these principles and understandings.

However the dimensions of taha wairua, taha tinana, taha hinengaro and taha whanau cannot be considered in isolation. Other dimensions of health and wellness that arise out of Maori beliefs and values have to be considered and one of the most significant of these is the values, beliefs and attitudes related to the whenua. Further discussion on Maori concepts of health and wellness is contained in Chapter Four. These values, beliefs and attitudes give a stark contrast to the medicalised model of health that is the experience of many persons coming into contact with some current health care delivery methods although many services would believe that they operated in a holistic culturally safe manner. It is also noted that it is the Maori worldview, te Ao Maori, that frames concepts of health so that for Maori a better descriptive word for health

that is that of Hauora. This term embraces the totality of values, beliefs and attitudes that is part of te Ao Maori.

- II. Maori research must be conducted by persons with cultural, reo, subject, research expertise and a commitment to things Maori.

Bevan-Brown (1998) believed that the researchers must possess a commitment to things Maori, the trust of the Maori community being researched, cross-cultural competence, personal qualities suited to doing Maori research, and an understanding of and commitment to the obligations, liabilities and responsibilities that are an integral part of Maori research.

There has been much discussion as to whether a non-Maori can fulfil this role. Arguments for and against have been put forward by a number of authors (Cunningham, 1998; Cram, 1997; Te Awekotuku, 1991; Teariki & Spoonley, 1991). These authors state that more important than a person's ethnic origin is their cultural, reo, subject and research expertise. While first preference for involvement in Maori research is unanimously Maori, if pakeha possess these prerequisite skills and qualities, it is acceptable, according to Bevan-Brown (1998), that they may engage in Maori research. A very strong point is made however that wherever pakeha are involved in Maori research, the control of that research should remain in Maori hands. Asking the questions that are contained in Table 1 ensured that a partnership was negotiated with Taranaki Maori and the researcher for the proposed study.

- III. Research should come from self-identified needs and aspirations of Maori. It should arise out of their self-identified needs and aspirations.

Stokes (1985) states that the "purpose of Maori research should be to identify and make available knowledge of the Maori world, Maori perspectives and perceptions, Maori cultural values and attitudes in areas which are seen as significant in Maori terms" (p. 6). Stokes also states that:

The more important and urgent function of Maori research is to direct efforts to investigating ways in which Maori resources – cultural, economic and social – can be used more positively and effectively, to work through institutional barriers, to provide avenues of guidance, set out options, and communicate these in such a way that Maori people

themselves can work through the issues that confront and concern them (p. 6).

It has been highlighted by a number of researchers (Stokes, 1985; Cram, 1997) that the Maori belief is that research simply for the sake of knowing is pointless and that there should be more specific aims and objectives in Maori research which are directed at helping people in their daily lives. The Aims of this study arose from the experience of the researcher observing whanau caring for their own with little assistance from health service delivery agencies. In discussions with local Taranaki Maori they stated that they did not always choose to do this, however they had no option but to care. They believed that the proposed study would be of benefit to them and identify needs in such a manner that they could then use the results for the future benefit of future whanau experiencing the effects of stroke in one of their members.

IV. There should be a positive outcome for Maori from the research.

There is no doubt from a reading of the literature (Cram, 1997; Smith, L.T., 1992a; Jahnke & Taiapa, 1999) that the past experiences between Maori and pakeha health professionals have left a legacy of suspicion about treatment and a reluctance to engage in interactions with such health professionals. Whilst these reactions have sometimes been interpreted as whakama, they may be more due to colonisation attitudes that gave Maori a history of being treated in patronising and paternalistic ways.

V. The people being researched should be active participants at all stages of the research.

Cunningham (1998) identified four types of research on a continuum beginning with research that does not involve Maori, and moving on through research involving Maori, Maori centred research to kaupapa Maori research. By his identified description and characteristics, this study would be classified as Maori centred research. Maori centred research has Maori involved at all levels of the research, as participants, researchers and analysts. Maori were the only participants in this research study and were the only members of the research team apart from myself.

VI. Maori research should empower those taking part.

It was believed that this empowerment should stem from both the research process and the product of it. Bevan-Brown (1998) cautions that researchers must plan carefully to ensure their participants are empowered and not merely used.

VII. Maori research should be controlled by Maori.

This control is crucial to ensure that the research project or study is carried out within a Maori cultural framework and that Maori interests and integrity are protected. The control of research involving Maori should extend to control in matters relating to ethical requirements, assessment, funding, intellectual property rights and ownership and dissemination of knowledge (Bevan-Brown, 1998).

VIII. Researchers should be accountable to the Maori community generally and the people they research.

Stokes (1985) makes the very strong point that: "There must be a high degree of Maori involvement at all stages, and the results of the research must be fed back by the researcher in such a way that obvious benefit accrues to Maori people themselves" (p. 19).

A powerful personal checkpoint for any researcher embarking on a project involving Maori is conveyed by Linda Smith (1992b) when she states that: "My findings that are relevant to Maori do not belong to me for my individual use, nor do they belong to any institution or employing authority. My research belongs to the whanau and the Maori community, it should empower the community to develop strategies that enable it to survive and to flourish" (p. 10).

IX. Maori research should be of high quality.

The use of Table 1 during the design of the study and in the development of the partnership between the researcher and local Taranaki Maori ensured that the study design would be of high quality and acknowledge the intellectual property rights of Taranaki Maori.

Application of the qualitative evaluation criteria devised by Leininger (Morse, 1994) would ensure a high quality study and the reader will be informed of the Maori world view of the issue under consideration. Whereas academic evaluation criteria as described by Leininger are necessary for a study audit at this level, Bevan Brown (1998) indicates that it is also necessary for a Maori centred research study to be assessed by culturally appropriate methods and measured against Maori-relevant standards. The Maori who constituted my research whanau were involved in the data analysis and development of the recommendations that arose from the study.

- X. Maori culture and preferences must shape the methods, measures and procedures used in the research.

For this requirement to be met a researcher must take into account the previous nine requirements of Maori research (Bevan-Brown, 1998) however it is important not to compartmentalise Maori knowledge in deciding what research method, measures, and procedures are appropriate for a specific research project involving Maori.

A very strong point is made in the cited work of Bevan-Brown (1998) that wherever pakeha are involved in Maori centred research the control of that research should remain in Maori hands. A commitment was made to this principle and adhered to throughout the study, from the early stages of planning and development, to obtaining the data, and through analysis and discussion of the findings of the study.

I had decided on a study into the whanau experience of caring for a member disabled with a stroke and had obtained the blessings, total support, and cooperation of Taranaki iwi. With all the readings, study and discussions I had relating to Maori centred research, particularly those related to my being a non-Maori researcher, I was now ready to begin my literature search. This would focus on epidemiological issues that would verify the seriousness of the incidence of stroke for Maori and underpin the worth of such a study.

## CHAPTER TWO

### EPIDEMIOLOGY OF STROKE – LITERATURE REVIEW

#### Introduction

A stroke event can be one of the most catastrophic events to affect an individual and their family due to the long-term disability and handicap that can follow such an event. A stroke episode in New Zealand health statistics is included under the general disease classification of ischaemic heart disease.

Maori as a group, are stated to have a higher rate of stroke than other identifiable groups in Aotearoa/New Zealand. As stroke, and its resultant disabilities, has a significant impact on the individual and their family, a review of the literature was undertaken. This literature review was examined the disparity between health statistics of Maori and non-Maori. It also specifically examined the impact of disability, and disability as a result of stroke. Aspects of whanau health and well being were also reviewed.

#### Definition

A stroke episode in New Zealand health statistics is included under the general disease classification of ischaemic heart disease. Stroke, correctly stated as a cerebral vascular accident (CVA) has been defined by the World Health Organisation (WHO) (1988) as: "rapidly developed clinical signs of focal or global disturbance of cerebral function lasting for more than 24 hours or until death, with no apparent non-vascular cause" (p. 108). Most strokes are ischaemic in origin resulting in cerebral infarction with the balance being due to intra-cerebral haemorrhage. Whatever the cause, the result is that brain cells are deprived of oxygenated blood and nutrition and die, causing the long-term disability and impairments that are seen following a stroke event.

The WHO includes subarachnoid haemorrhage in its definition of stroke but the Stroke Foundation New Zealand (SFNZ) (Baskett, 1996) has deliberately excluded this pathological entity from its national Best Practice Guidelines on the Management of Stroke. It is the location (area) in the brain and the extent of the cell death that determines the extent and type of the long term disability, impairments, and handicap that the person affected by stroke experiences.

## **Risk factors**

Whilst it is not the purpose of this thesis to discuss modification of lifestyle it does need to be clearly stated that there are a number of risk factors associated with stroke and that a number of these are avoidable.

The SFNZ (Baskett, 1996) identifies eight modifiable, or lifestyle, factors:

- raised blood pressure
- a diet high in saturated fat
- a diet high in salt
- a diet low in fresh fruit and vegetables
- heavy alcohol consumption
- physical inactivity
- use of tobacco
- being overweight.

To emphasise the importance of these risk factors the Stroke Foundation further states quite unequivocally that:

- one third of stroke events in people under the age of 65 years can be attributed to cigarette smoking
- almost half of all premature stroke can be attributed to a combination of smoking and the presence of hypertension
- Smoking or hypertension, or both, among people in the age group, may explain about 600 new episodes of stroke in New Zealand each year 35-64 years (Baskett, 1996, p. 16).

## **Independent life expectancy**

Independent life expectancy (ILE) measures health expectancy and is based on generalising life expectancy to include dependent disability. It is reported as the number of years a person can expect to live independently, without any self reported functional limitation. Together ILE, and the expectation of life with dependent disability add up to total life expectancy.

The Ministry of Health (MOH) (Ajwani, Blakely, Robson, Tobias, Bonne, 2003) states that ILE at birth for the general New Zealand population is estimated to be 65.8 years for males and 71.0 years for females (p. 22). These figures confirmed the earlier MOH (1999a) report "Our Future, Our Health" where it was stated that Maori have a significantly lower life expectancy than non-Maori. The

MOH (1999a) figures state that for Maori males life expectancy was 67.23 years and for Maori females 71.64 years, whereas non-Maori Males had a life expectancy of 74.27 years and non-Maori females of 79.61 years. In every age grouping, the ethnic gap in health status tended to widen further once a measure of disability was introduced. Maori not only live shorter lives than non-Maori, but also spend more years dependently disabled, both in absolute years (females) and as a proportion of their shorter lives (both genders). (Ajwani et al, 2003).

The life expectancy of Maori is 9.8 years less than that of non-Maori for women and 9.9 years less for men. Female life expectancy is cited as 80.8 years for non-Maori and 71.0 years for Maori whereas for men it is 75.7 years for non-Maori and 65.8 for Maori males (Ajwani et al, 2003).

At all ages, the ratio of ILE to life expectancy is less for Maori than for non-Maori. The 1996 figures cited by the MOH in their report (1999a) give an indication of the large burden of care by way of support to the dependently disabled that is visited upon the whanau. It will be shown that a large number of these whanau members dependently disabled with functional impairments, are as a result of stroke.

The MOH (1999a) further uses its epidemiological data to produce what is termed "Disability Adjusted Life Years" (DALY). A DALY is defined as an analysis of the burden of disease. It is obtained by combining the totals of premature mortality and disability outcomes. It is noted that the distribution of DALYs is heavily concentrated into older age groups. Maori are shown to bear a heavier burden of disease and injury than non-Maori with the 1996-97 figures showing that Maori experienced a 70% excess rate of DALYs lost relative to non-Maori (age standardised rates of 200 per 1000 and 120 per 1000 respectively) (Table 2) (MOH, 1999a).

**Table 2:** DALYs lost, by age, gender and ethnicity, 1996

	Age (years)					Gender		Ethnicity		All Persons
	0-14	15-24	25-44	45-64	65+	Male	Female	Maori	Non-Maori	
Number	50,820	46,415	88,303	144,033	233,612	282,144	281,040	81,738	481,446	563,184
Percentage	9	8	16	26	41	50	50	15	85	100
Rate	60	84	77	194	543	136	120	200	120	128

From: Ministry of Health (1999a). *Our health, our future Hauora Pakari, Koiora Roa: The health of New Zealanders 1999* (p. 34).

The burden of disease and injury was further analysed in terms of 11 major cause groups (Table 3).

**Table 3:** DALYs lost, by cause, group and gender, 1996

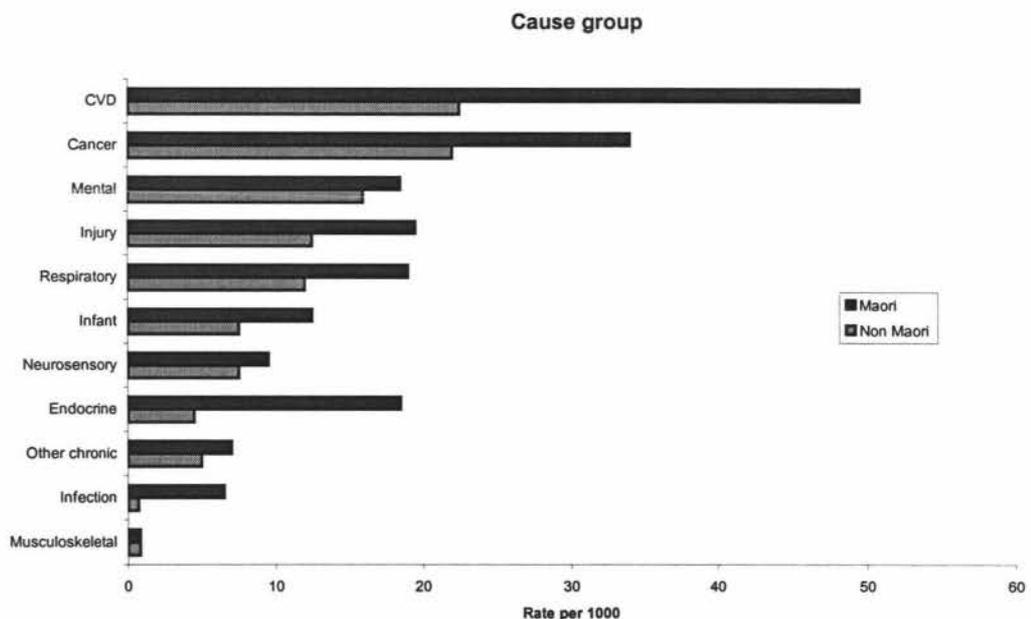
Cause group	Male			Female			Persons (all)		
	Number	%	Rate	Number	%	Rate	Number	%	Rate
Infection	8,215	3	4	10,055	4	4	18,270	3	4
Infant	11,615	4	9	10,127	4	8	21,743	4	9
Injury	34,905	12	19	14,679	5	8	49,584	9	13
Cancer	54,198	19	24	55,941	20	11	110,138	20	26
Endocrine	13,483	5	6	13,285	5	5	26,767	5	6
<b>CVD</b>	<b>73,444</b>	<b>26</b>	<b>31</b>	<b>62,946</b>	<b>22</b>	<b>19</b>	<b>136,391</b>	<b>24</b>	<b>25</b>
Respiratory	25,999	9	13	23,699	8	11	49,697	9	12
Other chronic	9,637	3	4	16,562	6	7	26,199	5	5
Musculoskeletal	6,886	2	3	11,361	4	5	18,247	3	4
Neurosensory	19,101	7	9	22,121	8	8	41,223	7	8
Mental	24,665	9	14	40,305	14	21	64,970	12	17
Total	282,148	100	137	281,081	100	118	563,229	100	127

**Note:** CVD: Cardio vascular disease

From: Ministry of Health (1999a). *Our health, our future Hauora Pakari, Koiora Roa: The health of New Zealanders 1999* (p. 34).

At the cause group level it is noted that cardiovascular disease (CVD) accounted for 24% of total DALYs, and that once standardised for age and gender, Maori had higher rates of DALY loss than non-Maori for most cause groups, especially for infectious diseases, endocrine disorders (mainly diabetes), cardiovascular disorders and respiratory diseases (Figure 1) (MOH, 1999a, p. 35).

**Figure 1:** DALYs lost, by cause group and ethnicity, 1996.



From: Ministry of Health (1999a). *Our health, our future Hauora Pakari, Koiora Roa: The health of New Zealanders 1999* (p. 35).

**Table 4:** Conditions causing at least 10,000 DALYs, 1996

Condition	DALY	Percentage of total DALYs	Major modifiable risk factors
<b>CVD</b>			
IHD	73,804	13.1	Smoking, high blood pressure, high blood cholesterol, physical inactivity, obesity, high fat low vegetable diet, diabetes High blood pressure, diabetes, smoking, physical inactivity
Stroke	30,115	5.4	
<b>Respiratory</b>			
CORD	27,848	4.9	Smoking Passive smoking, allergen avoidance Lack of vaccination (pneumonia influenza)
Asthma	18,800	3.3	
LRTI	11,621	2.1	
<b>Diabetes</b>	21,263	3.8	Physical inactivity, obesity
<b>Cancers</b>			
Colorectal	16,262	2.9	Low vegetable diet, physical inactivity Smoking, low vegetable diet, physical inactivity Lack of mammography screening
Lung	17,919	3.2	
Breast	13,522	2.4	
<b>Neuropsychiatric</b>			
Depression	20,497	3.6	Stress, physical inactivity Stress Physical inactivity, other stroke risk factors
Anxiety disorder	17,930	3.2	
Dementia	14,710	2.6	
<b>Injury</b>			
Road traffic injury	17,634	3.1	Speed, alcohol, non-seat belt use Depression, stress
Suicide	12,940	2.3	
<b>Osteoarthritis</b>	11,264	2.0	Obesity, physical inactivity

From: Ministry of Health (1999a). *Our health, our future Hauora Pakari, Koiora Roa: The health of New Zealanders 1999* (p. 35).

In the population as a whole specific conditions (subsets of the cause groups) were identified and whilst Ischaemic Heart Disease (IHD) ranked as the highest cause of health loss across all genders and ethnicities, stroke was the second highest identifiable cause of dependent disability. Among females stroke accounted for over 5% of the total burden (Table 3 & Table 4).

Durie (2001) states that deaths from stroke have been relatively stable for most New Zealanders but rates for Maori have fluctuated in an upward direction since 1988 and are now about one-third as high for non-Maori. The latest MOH report (Ajwani et al, 2003) continues to confirm that "cardiovascular disease, especially ischaemic heart disease, is a major contributing cause to the growth in life expectancy disparities between Maori and non-Maori non-Pacific people" (Durie, 2001, p. 43).

## Disability

Disability has been defined as functional or role limitation resulting from a health condition that is expected to last for six months or more (WHO, 1980). To further define these limitations 'functional' refers to limitations in the performance of basic actions or routine tasks required for everyday living. 'Role' limitations refer to the social activities of being a parent, a worker, a partner, a

kaumatua, or kuia. Basic self care activities such as eating, dressing, toileting and bathing are referred to as 'activities of daily living' (ADL).

There are a number of ways and methods of defining the characteristics of disability, and more importantly, its impact on the quality of life of the person with a disability. The MOH for its analysis of the levels of disability use the NZ Disability Surveys conducted by Statistics NZ in 1996, 1997 and 2001. A three level method of description of dependent disability, mild, moderate and severe is used to describe the impact on individual quality of life. For the purposes of morbidity data, dependent disability is disability associated with a need for personal assistance, whether from another person or complex assistive device, which corresponds to the levels moderate to severe. The three levels of definitions are:

- Mild – persons with no reported need for assistance.
- Moderate – persons with a reported met or unmet need for any of the following:
  - Special equipment
  - Help with
    - meal preparation
    - Shopping
    - Everyday housework
    - Finances
    - Communication
    - Washing
    - Dressing
    - Medication
  - Any met need received less frequently than daily
  - Work environment adaptations needed in present job, or for those unemployed or not in the labour force, to be able to work
- Severe – persons as for moderate but help received on at least a daily basis.

From the data collected during the 2001 New Zealand Disability Survey it was revealed that there were 743,800 people living in New Zealand with disability, a rate of 1 in 5 (20%) of the population. In the 1996/97 surveys there was a rate

of 239.0 per 1000 persons with a moderate or severe limitation related to disability. In the 2001 survey this figure had risen to 378.6 per 1000.

In considering epidemiological morbidity data it needs to be remembered that Maori and Pacific peoples have a much younger age structure than European/Other ethnic groupings. As a consequence, a superficial examination of rates of disability would show lower rates of disability for dependent disability however these rates do not show the significant age rate ethnic inequalities that exist (Figure 2) (MOH, 1999a).

Maori are more at risk of disability than non-Maori. In the 1996-97 figures the age and gender standardised dependent disability prevalence rate was 118 per 1000 for Maori as compared with 90 per 1000 for non-Maori. This is stated as "in keeping with the higher risk of both disabling chronic disease and injury experienced by Maori at most ages" (MOH, 1999a, p. 171).

A list of seven disease and injury causal group disorders that result in disability as stated by the Ministry, (MOH, 1999a), lists stroke as the second major classification of cardiovascular disorders resulting in disability. It is stated that stroke:

accounts for a greater share of dependent disability, and especially severe disability needing daily assistance with self care tasks, although it is less frequent than IHD as a cause of death. This is because stroke generates a wide range of functional limitations, covering all major types and sub types: agility, mobility, sensory, cognitive, speech, swallowing and incontinence (p. 186).

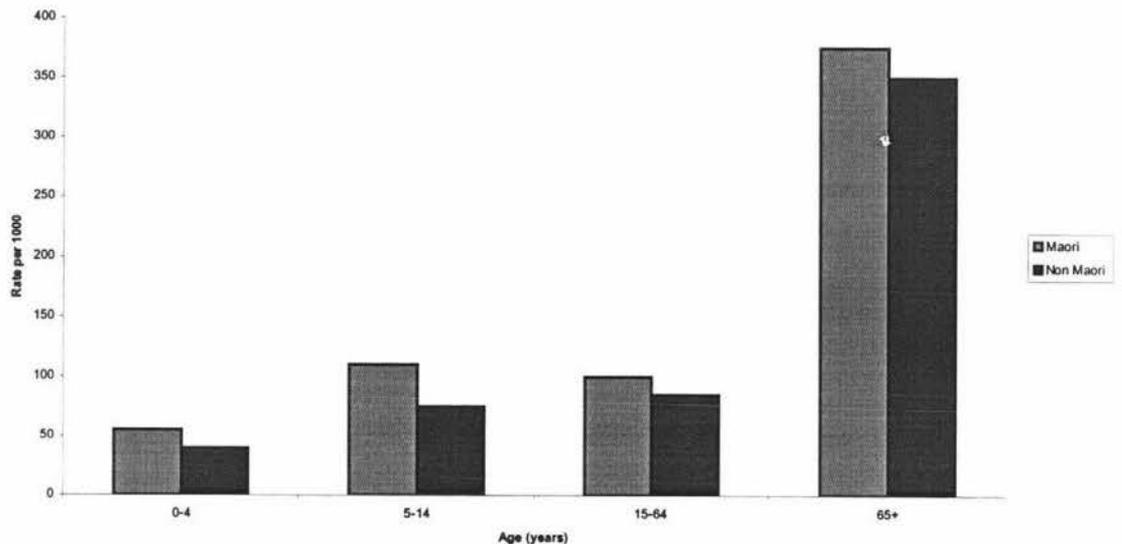
In Maori society the leadership roles for kaumatua and kuia increase with age, knowledge and wisdom. Unfortunately the leading causes of hospitalisation of kaumatua men and women are circulatory diseases, heart disease and strokes which contributes to a great deficit in the numbers of older people with the knowledge and leadership ability needed by the Maori community.

### **Incidence of stroke**

Stroke is included under the broad disease classification of Ischaemic Heart Disease. The Auckland Regional Coronary or Stroke Study (ARCOS) conducted from 1984 to 1993, on the incidence, prevalence, case fatality, outcomes and management of strokes among all residents of the Auckland Region during 1981-

82 and 1991-2 obtained very comprehensive figures. Whilst confined to the Auckland region these figures give an indication of the wider New Zealand population incidence. The results of the study have been reported by Bonita, Broad and Beaglehole (1993, 1997), and Bonita, Solomon and Broad (1997).

**Figure 2:** Dependent disability prevalence by age and ethnicity, 1996-97



From: Ministry of Health (1999a). *Our health, our future Hauora Pakari, Koiora Roa: The health of New Zealanders 1999*. (p. 174).

In 1991-92 the age standardised incidence of stroke in the Auckland population was 148 per 100,000 for males and 124 per 100,000 for females. After age 45, the lifetime risk of having a stroke was 1 in 4 for males and 1 in 5 for females. Approximately 75% of all first stroke events occurred in people aged 65 or older, and 50% in people 75 years or older. Maori and Pacific people had higher stroke incidence rates and higher stroke fatality rates than other ethnic groups (Bonita et al, 1997).

The 1991-92 ARCOS study estimated that about 50% of stroke survivors recovered without needing assistance for a residual disability within 12-18 months. However 30% were left with a Level 2 (moderate) disability (needing non daily assistance), and about 20% were left with a Level 3 (severe) disability needing assistance with at least one activity of daily living (Bonita et al, 1997).

When comparing the results of the ARCOS study with those of the NZ Disability Surveys, stroke has been estimated to account for 5% of the burden of severe disability and 3% of all dependent disability in the adult population. These

estimates therefore confirm stroke as a major cause of severe disability, especially if adjusted for the range and severity of the functional limitations involved. As a result stroke makes considerable demands on the health and disability support services and on families and communities.

The major stroke related disabilities are difficulties with speech, communication and swallowing; cognitive impairment; secondary depression and other psychological disturbances; weakness or paralysis of one or more limbs; incontinence, and difficulties with sexual functioning. The devastating consequences on mobility, activities of daily living and role fulfilment reflect the multiplicity of disabilities involved. The impact on family (whanau) and other informal carers can also be severe (MOH, 1999a, p. 208).

New Zealand reached a population total of four million people on 24 April, 2003 (Statistics NZ, 2003). The main ethnic groups were European, 80.0%, Maori 14.7%, Pacific 6.6%, and Asian 6.5% (Statistics NZ, 2003).

A MOH report (Nov 2001a) states that:

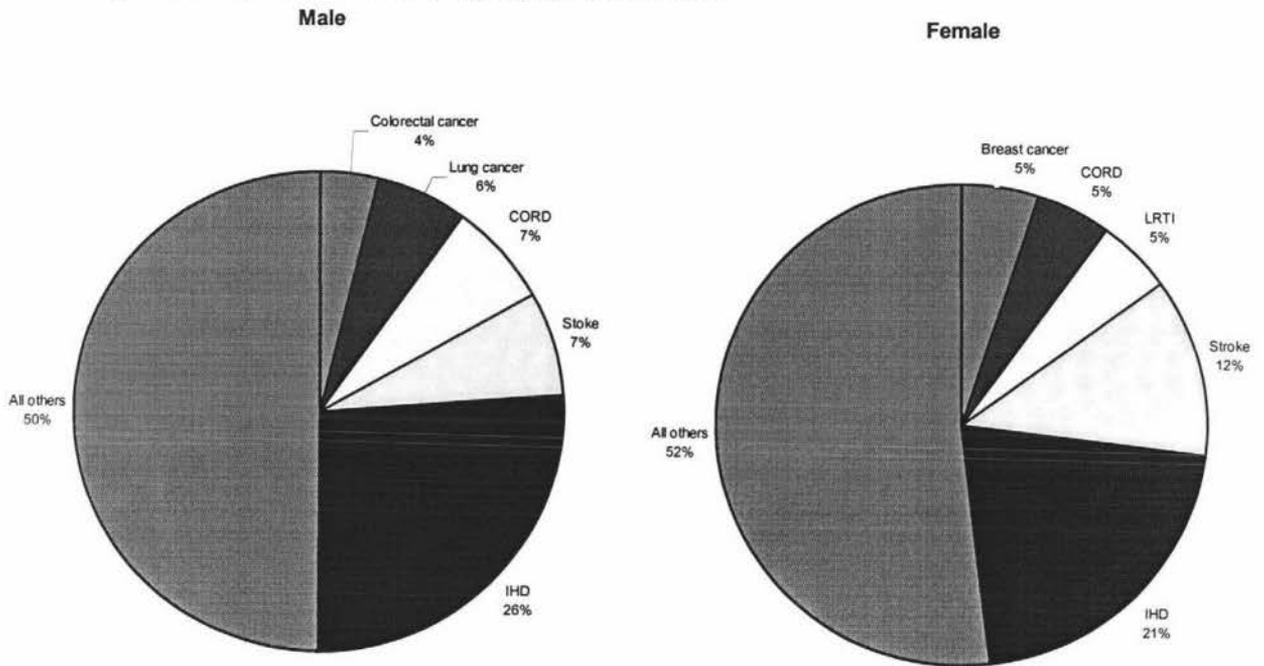
As in all OECD countries, most New Zealanders now die of (often multiple) chronic diseases. In 1996 chronic diseases accounted for 82.8 percent of all deaths, a proportion that has remained constant since 1986. Chronic disease mortality is dominated by cardiovascular disease (in particular ischaemic heart disease and stroke). The main causes of death by gender are summarised by the MOH (1999a, p. 28) Figure 2.

Cardiovascular disease is one of the leading causes of hospitalisation in New Zealand. In 1999/2000 over 45,000 people were hospitalised for some form of cardiovascular disease. Within CVD the main causes of hospitalisation are IHD, stroke and coronary heart failure.

Standardised mortality rates for IHD and stroke show that mortality for Maori was highest in 1998 with Maori being 85% more likely to die from IHD than European/Others.

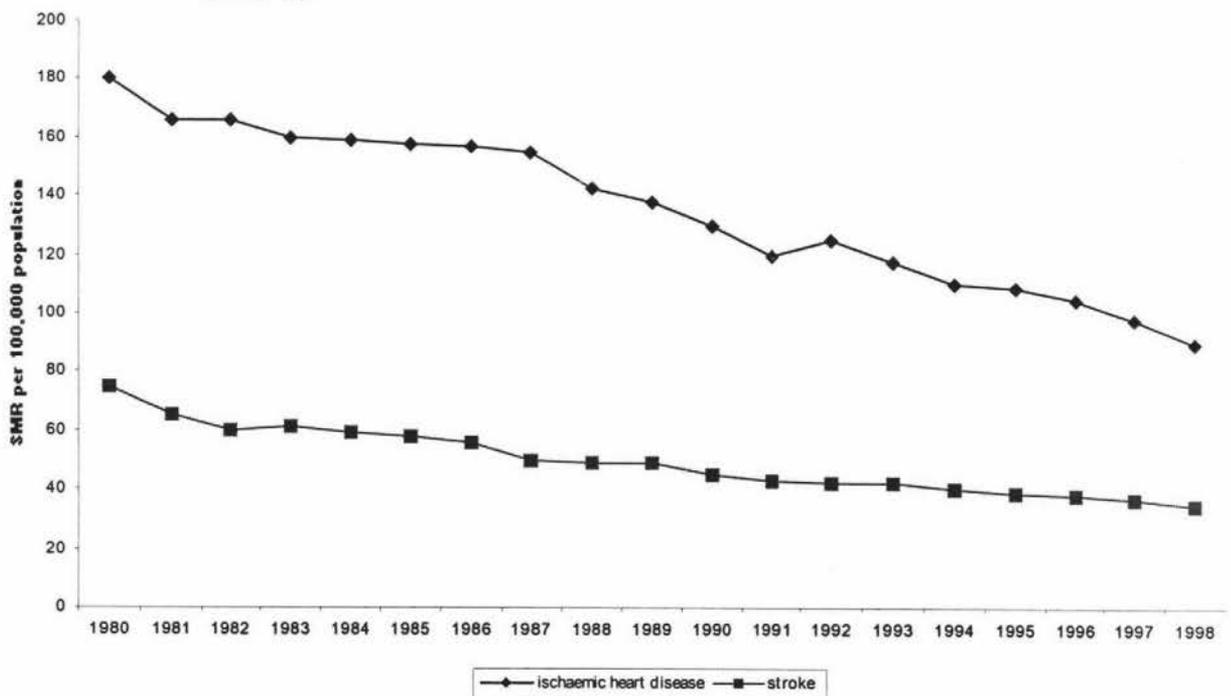
The death rate for stroke was 27% higher in Maori than European/Others in 1998. It is worthy of note that the IHD and stroke mortality rate have declined in all ethnic groups since 1996 with the reduction in deaths being highest for Maori with a reduction of 10.3% per year compared with 6.7% for European/Others (Figure 4) (MOH, 2001b).

**Figure 3:** Causes of mortality by gender, 1998



From: Ministry of Health (1999a). *Our health, Our future Hauora Pakari, Koiara Roa. The health of New Zealanders 1999.* (p. 19).

**Figure 4:** Standardised mortality rates for ischaemic heart disease and stroke, 1980-98



From: Ministry of Health (2001b). *The health and independence report.* (p. 60).

In 1997 the MOH set the following outcome targets in relation to the health and well being of older people and kaumatua affected by stroke:

- To reduce the stroke hospitalisation rate in Maori men aged 55 or more (from 1294 per 100,000 in 1995) to 800 per 100,000 by the year 2010
- To reduce the stroke hospitalisation rate in Maori women aged 55 or more (from 1340 per 100,000 in 1995) to 800 per 100,000 by the year 2010.

(p. 36)

I contacted the ARCOS study team mid 2002 and was informed that no figures on progress towards these goals would be available until at least mid 2003. As this thesis was published in October 2003, no figures were yet available.

### **Issues of service access and service delivery**

Issues of health service access and health service delivery are of particular importance to those persons and their families/whanau who have a disability. It appears almost inevitable, as the literature has shown, that the whanau member affected by stroke will have some level of residual disability. These issues have been identified in one way or another in nationally released documents over at least the past ten years.

The 1994 report for the National Advisory Committee on Core Health Services and Disability Support Services (Richmond, Baskett, Bonita & Melding, 1994) pointed out that 'aging in place' was an accepted world wide trend and that there was a need for "a national framework for comprehensive care services for older people in various settings both geographical (urban and rural) and cultural" (p. 8). Issues surrounding the availability of services and those factors that influence the accessibility to services were discussed. Identified factors that influenced service delivery included:

- Failure to realise that a need exists
- Insufficient resources
- Arbitrary decisions about who should or should not receive services
- Lack of information
- Inefficient organisation of services

- Devolution of services
- Difficult access to services.

(Richmond et al, 1994)

Richmond et al (1994) also identified that a "lack of options, choices and flexibility of services was also an issue" (pp. 38-40).

A 1995 Report, written for the National Advisory Committee, titled *He Anga Whakamana*, (Ratima, Durie, Allan, Morrison, Gillies & Waldon, 1995) looked at disability support services for Maori. One of the key findings was that Maori would have made more use of disability support services with improved communication and information. Recommendations that followed from the findings were made from the perspectives of the consumer, the provider, and the caregiver. Consumers saw the issue of improved information as "the most significant factor in improving access to services" (p. 20). Providers identified transport difficulties, financial problems, poor assessment and a lack of resources as barriers to access of services, whilst caregivers identified cultural sensitivity as a key issue. Perhaps the most important part of *He Anga Whakamana* was the development of a philosophy for disability support services for Maori.

The Health and Wellbeing of Older People and Kaumatua: The Public Health Issues (MOH, 1997a) pointed out "the ability to participate in and contribute to society is an important aspect of maintaining self esteem" (p. 24). The Report (MOH 1997a) specifically identified that even a comparatively minor stroke would require a community based rehabilitation service when the individual returned home from hospital. It was also highlighted that reliable, regular, public transport at a reasonable cost was necessary to allow older people to be active and independent, especially in rural areas. An emphatic statement was made related to care and support issues with the comment: "Co-ordination of carer and support services and access to respite and day care services could be improved" (p. 39).

Te Puna Kokiri and the Ministry of Health jointly funded Te Pumanawa Hauora of Massey University to prepare a report to enable a better understanding of the health and social needs of kaumatua (*Oranga Kaumatua: The Health and Well-being of Older Maori People*, 1997). One of the major findings from this study was that "disability support services were not often used by kaumatua and entitlements to some services and other State support was not well understood" (p. 12). Recognising this the authors of the report under the section on Policy

and planning implications reported: "Kaumatua expected improvements in health service delivery, especially in relation to cost, location transport and Maori cultural values" (p. 13). In this report it is also stated by over a third of all kaumatua interviewed, that health service delivery would be improved by more home visits from health professionals.

Barriers to Maori of access to health services were identified as being associated with issues related to cost, location, cultural and structural barriers in Whaia Te Whanaungatanga: Oranga Whanau (MOH, 1998). It was also noted that "Whanau are the best guides through their own world views" in minimising barriers of access to services (p. 35). Co-ordinated holistic approaches to delivery of health services were stated to be particularly important for isolated and rural communities.

Of significance for this study was the literature review undertaken by The Clearinghouse for Health Outcomes and Health Technology Assessment (1999) that examined 'Rehabilitation of cerebrovascular disorder (stroke): early discharge and support'. There were two specific conclusions reached from their critical appraisal of the literature that were applicable to this study and these were:

- Home based services do have a role to play in the rehabilitation of stroke patients, and
- Current evidence supported the use of domiciliary occupational therapy in patients following a stroke.

The Ministry of Health publication Reducing Inequalities in Health (MOH, 2002d) examined very carefully the issues surrounding inequalities in health that exist among groups of New Zealanders. A framework was produced that targeted Health and Disability Services and itemised improved access, improved pathways through care, and the need to take a population health approach to the needs of those currently affected by socioeconomic inequalities in health.

The second New Zealand Coalition Government led by Labour has taken some significant initiatives in the direction of how health and disability support services should be implemented and their development has been guided with the release of a number of 'Strategy' documents.

The first of these was the New Zealand Health Strategy released by the MOH in December 2000. The Foreword to this document written by the Minister of Health

states quite unequivocally that the Strategy "provides the framework within which District Health Boards and other organisations across the health sector *will* operate" (p. vii).<sup>1</sup>

This Strategy identified seven "fundamental principles that should be reflected across the health sector." These were:

- Acknowledging the special relationship between Maori and the Crown under the Treaty of Waitangi
- Good health and wellbeing for all New Zealanders throughout their lives
- An improvement in health status of those currently disadvantaged
- Collaborative health promotion and disease and injury prevention by all sectors
- *Timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay*<sup>2</sup>
- A high-performing system in which people have confidence
- Active involvement of consumers and communities at all levels (p. vii).

Further itemised were five service delivery areas on which the Government wished the health sector to concentrate in the short to medium term and the fifth of these was: "accessible and appropriate services for people living in rural areas" (p. viii).

The NZ Health Strategy was followed by the release of The Primary Health Care Strategy (MOH, 2001e). Whilst many of the services required by the whanau member affected by stroke would more correctly be classified as secondary health and disability service care, there were identified significant pointers towards that service delivery provision. Barriers to accessing primary health care that reduced access to health and disability services" were identified. It is stated that there was a "need to be open to providing services in a range of different settings, for example in people's homes, workplaces, in schools, or on marae" (p. 16).

In chronological sequence the next Government planning document to be released was The New Zealand Disability Strategy (MOH, 2001h). The long term aim of this Strategy is to see the development of New Zealand as an all inclusive society. It is correctly pointed out that people do not have disabilities, that people have impairments, and the barriers raised by society are what result in

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<sup>1</sup> Emphasis not in original

<sup>2</sup> Emphasis not in original

disability. Fifteen objectives underpinned with detailed actions are given in the Strategy. Service provision and transport issues are identified as factors that impact unfairly on the life of the disabled person.

Objective 11 specifically identifies the need to promote participation in Maori society and society in general. As the residual disabilities associated with stroke often deny such participation by older Maori, the kaumatua, the actions detailed as necessary to meet this Objective are very important to Maori whanau, hapu and iwi.

The New Zealand Positive Aging Strategy (Ministry of Social Development, 2001a) was released in 2001 after a widespread consultation process. Ten Positive Aging Goals and Key Actions were identified. The second goal was simply labelled 'Health' and stated as its goal: "Equitable, timely, affordable and accessible health services for older people" (p. 20). Also of significance in this Strategy document was the Action statement 4.3 under Transport: "To ensure lack of transport is not a barrier to accessing health services" (p. 21). This supports the 'Rural' goal actions 7.2 "Improve service delivery to rural areas;" 7.3 "Ensure policies address the additional costs associated with providing services to sparsely populated rural communities;" and 7.4 "Ensure equity of access to health services for people in rural areas" (p. 22).

The Health of Older People Strategy (MOH, 2002d) was released in April 2002 after an eight month consultation process with interested parties. It contains many perceptive comments and recommendations that affect the elderly, particularly those with a residual disability following a health crisis such as the event of stroke.

The eight objectives of the Strategy where change has been deemed as essential are:

1. Older people, their families and whanau are able to make well-informed choices about options for healthy living, health care and/or disability support needs
2. Policy and service planning will support quality health and disability support programmes integrated around the needs of older people
3. Funding and service delivery will promote timely access to quality integrated health and disability support services for older people, family, whanau and carers

4. The health and disability support needs of older Maori and their whanau will be met by appropriate, integrated health care and disability support services
5. Population-based health initiatives and programmes will promote health and well-being in older age
6. Older people will have timely access to primary and community health services that proactively improve and maintain their health and functioning
7. Admission to general hospital services will be integrated with any community-based care and support that an older person requires
8. Older people with high and complex health and disability support needs will have access to flexible, timely and co-ordinated services and living options that take account of family and whanau carer needs (pp. 1-2).

Actions and Key Steps in implementing these objectives are given in the Strategy and contain much that offers to improve the life of older people and their families and whanau needing health and disability services.

The final Strategy document reviewed was He Korowai Oranga: Maori Health Strategy (MOH, 2002a). This document is focused on the needs of the whanau. Whanau are recognised as the foundation of Maori society and asks that "the health and disability sectors recognise the interdependence of people" (p. 1). The Strategy continues on with two broad directions, three threads and four 'Pathways for Action.' It is the third of these pathways 'Effective health and disability services' that contains much of relevance to the support needs of the whanau of Taranaki. Taranaki has an essentially rural population and Objective 3.2 of this Pathway discusses the need for DHBs to improve the access to, and the effectiveness of mainstream services. Recommendations made under Objective 3.3 related to the need to provide the highest quality service were reinforced as this research study progressed.

Having examined the epidemiology factors surrounding stroke that verify that this is a major issue for health care providers in New Zealand, and therefore for those affected by stroke, in particular for our Maori population, I now move on to examine rehabilitation and disability support services in the New Zealand context. This has particular application to an understanding of the health service delivery available to Taranaki whanau affected by stroke.

## CHAPTER THREE

### REHABILITATION AND DISABILITY SUPPORT SERVICES IN THE NEW ZEALAND CONTEXT

#### Introduction

In obtaining the necessary insight and information to enable me to write this chapter I drew on my own experiences working for a very large hospital board during the implementation of the majority of these reforms; extensive readings of available documents, particularly those of the various Taranaki Health Care managements available in their hospital library that covered the period; and the in depth analytical works of Gauld (2001), Davis and Ashton (2000), and Bloom (2000). In particular I am grateful for the personal communications I had with key players in the field who lived and worked in Taranaki through those times. To ensure a free and open disclosure an assurance of anonymity was guaranteed to these persons.

Any examination of the current situation of rehabilitation and disability support services needs to be considered in light of the long term influence and effects that the 1990's health reforms have had on the administration of such services. In fact the reforms attributed to the 1990's actually began in 1983 with the first major restructuring of the public health system in the modern era in Aotearoa/New Zealand. The era of reforms was ushered in with the then Government introducing the formation of Area Health Boards (AHB) that were to see an amalgamation, and therefore disappearance, of many small Hospital Boards.

Gauld (2001) points out that the move to reform the public health system needs to be understood as a worldwide phenomenon that was occurring at this time. Literally every developed country, and many developing countries, engaged in substantial health sector restructuring at this time. New Zealand politicians observed, and caught up with the Fourth Labour Government's public sector reform movement, the existing public health system was seen as a ripe target for attention. Public health service delivery at this time was typified by public hospitals being managed by elected hospital boards.

To understand why the reform movement focused upon the New Zealand health system one needs to remember that in the years prior to 1990 the medical profession held the dominant position. I have heard it described as paramouncy, as it was evidenced by even casual observation that the lay

elected members of the hospital boards and other health professions subordinated themselves to the medical profession. There was a system of tripartite management in place with the Medical Superintendent occupying top position followed by a Nursing Matron, and a House Manager. There was little financial responsibility with an attitude that if the local board decided such an expense was necessary, whether it be a new building, or piece of equipment, then Government would provide the ready cash.

### **Setting the scene**

Health service delivery came under increasing threat as the Government moved to reform the public sector in the late 1980's. The passage of the State Sector Act in 1988 required new management approaches in hospitals and the Public Finances Act of 1989 required AHBs to implement new financial practices and accountabilities.

The Labour Government had instigated an era of great uncertainty within the health sector. The political leaders of the early 1990's alienated and disenfranchised the officials that administered the health sector as they increasingly turned to the use of 'consultants' for advice. This use of non-Government sources particularly bypassed the senior staff of the Department of Health (DoH), supposedly the Government's advisors, in all matters of health policy (Davis & Ashton, 2000, pp. 51-54).

Much of the uncertainty within the health service from a local level through to the Ministry of Health was created by the changes in the Ministerial portfolio of health with there being three separate Ministers in the three years 1987-1990. Each Minister brought their own philosophy and view to the health portfolio and while they settled into the job every initiative and action was held over and then often changed from the previous Minister's directions. Gauld (2001) reports that staff morale noticeably began to fall as a consequence of these stop start directions from central Government.

Government aims that were postulated as the rationale for the passage of the Area Health Boards Act 1983 were variously stated as integration, co-ordination, local self-determination and community participation in health care (Bloom, 2000). As part of this reformation of health service delivery, not only were small Hospital Boards to be amalgamated but the local District Offices of the (then) DoH were to be absorbed into the new AHB structure. An example would be the disappearance of the Hawera Hospital Board, the Opunake Hospital Board and

the New Plymouth District Office of the DoH. It may be argued that the Taranaki Hospital Board also disappeared, however reality shows that the newly formed Taranaki Area Health Board that was finally formed in 1989/90 (one of only 14 formed by this time) from a merger of all three Boards and the local Health Department office was simply the old Taranaki Hospital Board under another name. The major flaw in this first 'reform' of the health system was that it was voluntary and there were many delays to amalgamation into AHB configuration due to vested interest and self-preservation.

These delays in the amalgamation of hospital boards and the local area offices of the Department of Health only confirmed to the Government and its external advisors that reform was necessary. There was an increasing emphasis on market orientated management techniques as an alternative to State control management of the health sector. Private sector management practices, the step immediately prior to corporatisation, were to be the salvation of the public health sector (Gauld, 2001). Competition and contracting were to be the guiding principles for organisations such as hospital management and policy was to be split from service delivery.

## **1990 to 1996**

The next phase of the health reforms occurred in 1991 when the National Party was elected the Government and signalled its intentions, with the release of the "Green and White Paper," to make the restructuring of health service delivery compulsory. It proceeded to do this in 1993. Gauld (2001) describes what happened on budget night, July 1, 1993 as the 'big bang' when all AHBs were abolished. Management of public hospitals passed to interim Commissioners, and the hospitals were now to be known as Crown Health Enterprises (CHE). These CHEs were required to make a profit and to operate on private sector management principles.

It is interesting to note that of the 23 CHEs that were created most of the Chief Executive Officers (CEOs) appointed to guide and direct them had no prior background in health and had been recruited from the private sector. In fact only three of the 23 had any health background. Within three years 20 of these appointed CEOs that heralded in the Government's new era of accountability and efficiency in the health sector had resigned (Gauld, 2001).

Staff morale throughout the country fell further as the patient focus of hospital staff was suborned to the business and profit directions steered by CHE

managers. To health professionals working at the bedside it seemed that there was little regard being paid to issues of patient safety or service delivery standards. In one personal communication the process of change that occurred at this time was described as: "change management by chaos. These guys, Simon Upton and such, were prepared to take it on, head on, and I have to say [sic] blew it up. They literally blew it up. The organisation was in crisis, the sector was in crisis." (personal communication, April 31, 2003).

However the most significant change that occurred with the 'big bang' was the funder divider split which separated the provision of health services from the funding of them. Four Regional Health Authorities (RHAs) were created to contract for services from within both the public and private health sectors. These RHAs had enormous power. This was an inevitable outcome in a situation where there was only one funder. It soon became apparent that the RHAs were actually interfering and imposing policy decisions by the simple expediency of stating to a negotiating CHE: "we won't fund that." It was during these times that CHEs looked at the market and began to withdraw themselves from services they decided no longer were to be included in their Core business. The most obvious of these seen throughout the country was the decision to close down long stay wards for care of the elderly, and slow stream rehabilitation wards.

The public never accepted these health reforms and health professionals resented the profit motive that put the dollar before patients. It was felt by many employees that whereas staff had always been the greatest resource for the local hospital they were now viewed by management as their greatest liability. Health professionals felt devalued and the work they did unappreciated. Government's great hope that the reforms would see a limitation of service costs and the ability to do more for the same money was never realised. Costs blew out in every CHE and they consistently failed to meet projected business plan targets. Simply put, the health reforms had failed to achieve their aims (Gauld, 2001; Davis & Ashton, 2000).

## **1996 to the present day**

In 1996 New Zealand held its first Mixed Member Proportional representation election that resulted in the National/New Zealand First Coalition Government. As a result of the negotiations to form that Government the 're-reforms' were ushered in. The profit motive for the operation of public hospital services was removed although they still were required to operate in a businesslike manner.

CHEs now became Hospital and Health Services (HHS). Purchasing of services was to be centralised, that is the four RHAs were to be combined into one national funder for services.

The impact of the move to one central funder, the Health Funding Authority (HFA), was to create a very powerful player in health service delivery. The HFA controlled most of the health budget and therefore its policy steering capacity was substantially greater than that which was wielded by the RHAs. Changes emanated at the behest of the HFA and not from central Government (Gauld 2001). The Ministry of Health (MOH), formed out of the reformation of the Department of Health (DoH) when all the Regional and District offices were closed, struggled to have any influence or a voice heard.

Staff morale continued to fall as the public hospital sector continued to downsize. The requirement to operate in a business like manner meant that staff were the first to feel the brunt of budget cuts and, words to the contrary, staffing levels were cut across the board. Budget constraints imposed by the HFA forced every HHS to cease providing selected services, a move that had been started by the RHAs. The final move in this period of re-reform of the health service began in 1999 with the defeat of the first coalition Government and the election of the second, this time a Labour/Alliance Government. For staff in the public hospital sector it seemed that it had become a routine consequence that with a change of government there was to be a major restructuring of the health system.

With the change of government in 1999 out went the HHS structure and in came District Health Boards (DHB) with the public once again being able to elect some members of these, however Government retained the right to appoint a number of board members so as to ensure business acumen and cultural balance. For staff it merely seemed that these politically induced changes occurred just as the health sector was beginning to recover from a previous bout of restructuring. The cynics were heard to state that changing the structure did not bring better health care delivery; it merely altered the structure within which services continued to be delivered.

### **Changes in health service delivery in Taranaki**

So what did these turbulent times mean for the delivery of health care and for staff employed in the public health sector in New Plymouth and Taranaki? Midland RHA, as the funder of provided services for this area forced the major changes in the delivery of health services in Taranaki. It must be emphasised

that these changes by the Midland RHA were forced right across the central North Island from large Boards such as Waikato through Taranaki, Tairāwhiti and Lakes as we know them today.

From personal communications I have had with key players in the health sector in Taranaki through these times a broad picture emerges of the pervading influence of the Midland RHA on policy and restructuring of service delivery. One of the most significant changes that occurred, certainly as far as the public was concerned, was the exiting of long term continuing care of the elderly. The RHA had been paying the Taranaki Board more than it paid to rest home residential care providers per bed. It is said that the quality of care in those Taranaki hospital beds was higher than that provided in the rest homes but for the RHA, the funder, raw price was what mattered (personal communication, 7 April, 2003).

From the perspective of my interest in rehabilitation services, the changes that were wrought on Assessment, Treatment & Rehabilitation Services (AT&R) were significant. There was an across the board imposition of a generic rehabilitation philosophy. As it was described to me, the Midland RHA decided that there was no real need for a stand alone rehabilitation service; that in fact there was no need for a dedicated AT&R service. The rehabilitation service in operation in Taranaki in the early 1990's is described thus: "We had the kind of service that most places in the country are now suggesting they would like to have and its really very sad" (personal communication, 9 April, 2003).

At Taranaki Base hospital a purpose built unit for the AT&R Service was the envy of many and received visitors from throughout the country. However by 1992 the new service management in place at the Board, with the emphasis guided from the example of Government who listened more to external advisors than their own health professionals and clinicians, made the decision to take this facility away from AT&R and convert it into a unit for Mental Health services.

I think there is no doubt that AT&R got a bad deal out of all that. A shocking deal. They had a facility that was planned years before it was built. It was a lovely facility and very well set up. They lost the lot and ended up over in Ward One (an acute medical ward) with a lower number of beds (personal communication, April 31, 2003).

However the biggest operational influence brought about by Midland RHA was the development of service management and the imposition of a philosophy that

stated that rehabilitation should occur at home or in the community. "Midland believed the distinction between when somebody went from acute medicine to AT&R, pure rehab, was an artificial one created by health specialists [sic]. They had a view that AT&R and acute medicine should be integrated" (personal communication, 7 April, 2003).

What the service delivery contract negotiators of Midland RHA argued in Taranaki, as in Waikato and other areas under their influence was that it was better to stay in an acute ward for a bit longer and then have the ability to transfer to a rest home or one's own home for community based rehabilitation.

In purely logical terms the idea had a lot of worthiness. In practical terms it was unworkable. I think the funder took a very purest approach to it rather than trying to be pragmatic about leading and managing change. I think all those things led us to a particular place which is the legacy that means we are quite out of sync [sic] with other regions today (personal communication, April 31, 2003).

The practical implementation of this philosophy saw the Taranaki AT&R Service as existed in the early 1990's destroyed. The purpose built unit with specifically designed rehabilitation facilities was taken from the Service; the psychogeriatric services and staff were reallocated to the mental health service; the dedicated AT&R allied health personnel were removed from reporting directly to the Service; and the dedicated doctor led South Taranaki Community Team and its two days a week operations ceased to exist.

The removal of the dedicated allied health personnel was possibly more related to internal reorganisation of service delivery at Taranaki Base Hospital rather than the restructuring of the AT&R service however these changes came at the same time as there was huge pressure being applied to AT&R to integrate into acute medicine. The dilemma that arises relates to professional lines of accountability versus clinical lines of accountability. For the present day AT&R service they merely see that when there is a physiotherapist or occupational therapist short somewhere else in the hospital then they do not have one that day.

The third major impact felt from the influence of Midland RHA was the putting out for tender of the contract to provide Needs Assessment Service Co-ordination (NASC). Formerly a service provided by the hospital I believe only Waikato was successful in managing to be awarded the contract when the tender

process closed with Midland. Some in AT&R at Taranaki feel this was a retrograde step and would like to see the NASC agency brought back under the control and influence of the hospital. Opinions vary and some I have talked to are quite emphatic that it should stay with a private service provider. It is believed by these people that the orientation of NASC services within a hospital environment becomes a medically based model. It is felt that for Maori families this model failed to engage families in a more appropriate way. It was emphasised by one informant that needs assessment is much broader than just assessing one's medical needs. It is the social and cultural needs that follow on from medical needs that tend to be overlooked in a hospital based NASC service.

### **Current status of disability support services**

I believe it is significant that an analysis conducted by the National Health Committee, Health and Disability Services for Older People: a draft document for consultation (March 1999) in effect slated the Midland RHA. In the executive summary of this report the 1993 health reforms are stated to have "sought to improve services for frail older people through...incentives to invest in rehabilitation" (p. 4). The approach taken by Midland RHA (and the Central RHA) were analysed as "not appropriate for most frail elderly" (p. 12). The report went on to say that:

The use of generic rehabilitation services in some areas has resulted in significant reduction of specialist AT&R services for older people, particularly in the Midland area, at a time when these services should be consolidated in preparation for growth in older populations and the associated pressure on services and budgets that this will bring. Reduction in specialist AT&R services risks adverse outcomes for older people, and use of more expensive services where irreversible conditions that are not addressed deteriorate" (p. 12).

The creation of one central funder out of the four former RHAs resulted in the HFA. This in turn has since been absorbed into an expanded MOH, which is reclaiming its expert advisor status to Government and Ministers of the Crown. The HFA as it was structured developed several 'Operating Groups' that produced a number of reports and recommendations that are still influencing policy today. Its Disability Support Services Operating Group specifically targeted Maori as being low users of disability support services (HFA, 2000).

Disability Support Services (DSS) are intended to focus on the reduction of barriers experienced by those New Zealanders that experience long-term functional and role impairment. Many of the barriers disabled persons face are located within the environment and are not necessarily due to the personal disability. An example of this was to be found in the number of whanau who related that transport issues were handicapping their loved one. A lack of access and/or egress and an inability to obtain ready means of actual transport made the opportunities of life very limiting to them.

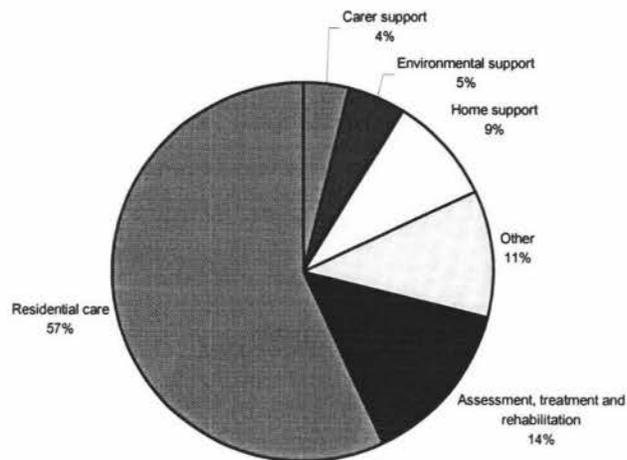
The DSS services provision has three processes:

- Needs Assessment: This begins the process whereby the actual care and support needs of the disabled person are identified. It is the intent of the process that these needs be identified irrespective of funding constraints or the availability of services.
- Service Co-ordination: During this phase of the process the most appropriate services and support options are determined to meet the assessed care and support needs. These may or may not be provided by the local DHB community services, with more appropriate service provision coming from private service providers. The MOH funds all service provision.
- Service Provision: Identified care and support services can include:
  - help with activities of daily living (personal cares)
  - help with household activities
  - caregiver relief with respite care and day care provision
  - rehabilitation services
  - environmental services such as equipment provision and home alterations. (MOH, 2001b, p. 84).

The New Zealand wide budget for DSS services is in excess of 1.5 billion dollars and is increasing by approximately 6 to 7% per year. It is stated that 89% of DSS expenditure is spent on: residential care, assessment, treatment and rehabilitation, home support, environmental support, and carer support (Figure 5). These are all categories that are, or should be, used by the whanau of the stroke affected person living at home (MOH, 2001b).

The New Zealand Disability Strategy together with the Maori Health Strategy highlights the issues facing the whanau and disabled Maori. Essentially these are the need for more culturally appropriate, competent, effective support services. The MOH (2001b) is working with Maori "to enhance and facilitate the development of Maori-based support services; and to improve access for Maori to existing mainstream support services" (p. 105).

**Figure 5:** DSS expenditure by service area, 2000/01



From: Ministry of Health (2001b). *The health and independence report*. (p. 87).

A broad picture has been given that enables the reader to put into context the situation in Taranaki today. New Zealand Governments embraced the health reform movement that affected much of the world throughout the late 1980's and early 1990's and an era of change was implemented which in many respects continues. It is important to have some understanding of these influences so that one does not harshly judge the current situation in Taranaki today with health care service delivery.

It is the basis of these changes and how they were implemented in Taranaki that in the next chapter leads to an examination of the influences that may have an effect on Maori health issues both nationally and locally.

## CHAPTER FOUR

### ISSUES OF MAORI HEALTH

#### **He Korowai Oranga – The Maori Health Strategy**

He Korowai Oranga: The Maori Health Strategy, (MOH, 2002a) has as its focus “whanau ora” – healthy families.

There are four pathways identified to improve Maori health. These are:

- Whanau, hapu, iwi and Maori community development
- Maori participation throughout the health and disability sector
- Effective health and disability services to Maori – the focus on reducing inequalities, improving mainstream services, improved access, service quality and health information
- Intersectorial action that works across the sectors to co-ordinate social service delivery for whanau (p. 9).

An earlier report from the MOH (1997a) states very clearly that:

being in their own home, in a familiar marae environment, being able to contribute to their community and pursue their own interests engendered a sense of well being and value for kaumatua. Kaumatua were also usually involved in caring for other whanau members, including children, those with a disability and frail older people (p. 26).

This statement reinforces the reality that the presence or absence of a live-in carer is a crucial factor in determining whether an older person with a (moderate or severe) disability can remain in their own home. An explanation of the ‘levels’ of disability is to be found in Chapter Two of this thesis.

Disability has been defined to enable a distinction to be made between a disability and a personal health need. A personal health need was stated as: “where a person’s level of independent function is reduced by a condition which requires ongoing supervision and treatment from a health professional that person is considered to have a personal health need rather than a disability.” (Ratima et al, 1995, p. 3).

The MOH at the same time, defined a person with a disability as one who had a condition from this list:

- Physical disability: reduced physical capacity
- Sensory disability: impairment of senses
- Psychiatric disability: continuous or intermittent disorders of thought, feeling, volition or behaviour
- Intellectual disability: permanent impaired learning ability which prevents or inhibits the development of physical and social skills
- Age related disability: physical, intellectual or psychiatric conditions related to old age. (Ratima et al, 1995, pp. 3-4).

### **Whaia Te Whanaungatanga: Oranga Whanau.**

Whaia Te Whanaungatanga: Oranga Whanau (MOH, 1998) has some very important comments regarding whanau and whanau health issues of importance in developing the study. "Understanding Maori culture, values, norms and perspectives is vital in the collection, collation, storage and access to information relating to Maori (and by implication whanau) health" (pp. 49-51).

This MOH (1998) study points out that there is a conflict between the health and disability sector and the values and beliefs of Maori due to the sector holding that the rights of individuals supersede those of collective Maori such as whanau, hapu and iwi. Both the Privacy Act 1993 and the Code of Rights promote individual rights and priorities. The approaches promoted by these Acts deny the reality of the role of whanau and hapu to act as support systems for individual Maori and the contribution that whanau makes to attainment of health and the maintenance of wellbeing for each of their members.

### **Maori concepts of health**

The Maori definition of health is essentially holistic with the wellbeing of an individual being dependent not only on the absence of disease or illness, but also upon historical, social, cultural, economic, political, and environmental circumstances. These concepts and influences are better described with the integrative term '*hauora*' rather than the bald term of "health" with all the western medicalised imagery that this conveys. Durie (1985) has quite correctly pointed out the importance of the land (the whenua), the language (te reo), and

the family (the whanau), as institutions of health. He further states that the differing perspectives of Maori health "sought to widen understandings of health, to translate health into terms which were culturally significant, and to balance physical and biological approaches with cultural and sociological views" (Durie 1994a, p. 78). Perhaps the most significant of these historical, social, cultural, economic, political and environmental circumstances relate to the whenua. An ancient Maori proverb (whakatauki) captures some of the intangible powerful feelings of attachment that Maori have for the land:

Ma te wahine ka tupu ai te hanga nei, te tangata;  
 Ma te whenua ka whai oranga ai.  
 Whai hoki, ki te tangohia to wahine e te tangata ke,  
 Ka ngau te pouri ki roto I a koe.  
 Na, ki te tangohia te whenua e te tangata ke,  
 Ka tapu to pouri ano.  
 Ko nga putake enei o te whawhai.  
 Koia I kiia ai,  
 He wahine, he onene, I ngaro ai te tangata.

Woman alone gives birth to mankind,  
 Land alone gives man his sustenance.  
 No man will lightly accept the loss of  
 His beloved wife, nor that of his sacred land.  
 It is said truly that man's destroying passions  
 Are the love of his wife and the love of his land.<sup>3</sup>

(King, 1975, p. 115)

Whilst it is true that many Maori have been separated from their land through urbanisation and the processes associated with colonisation many Maori today continue to have an extremely close spiritual relationship with the land. Maori beliefs and values follow their kaupapa all the way back to Papatuanuku, the earth mother, and Ranginui, the sky father. It is to Papatuanuku that many Maori turn to in times of great stress, times of great need, and as the God to honour in many rituals. Ties to the land are expressed through the whenua also being the word for the placenta, and are a further example of the sacred belief and importance that the land has for Maori.

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<sup>3</sup> To honour Maori intellectual property rights I have endeavoured to discover the ownership of this whakatauki. Douglas Sinclair of Ngai Tahu used it in a contributory chapter in the Michael King publication "Te Ao Hurihuri", 1975. Te Maire Tau, currently acknowledged Ngai Tahu historian, informs me that this is a generic whakatauki and does not have its origin with Ngai Tahu. No offence is intended in not acknowledging its origin.

Many of the concepts and influences of health status are interrelated and integrated in a number of models of and for Maori health. With the emphasis on the whanau in relationship to health and wellness, the Whare Tapa Wha (four cornerstones of the house) model of Maori health is used to describe the caring of the whanau. In this model, as defined by Durie (1994a) there are four dimensions or themes that contribute to wellbeing:

**te taha wairua** – it is taha wairua that links human capacity with the environment. The Mauri (life force) is the link between the individual and the spiritual dimension. Whilst taha wairua encompasses a belief in a God this is but only one expression of wairua. The relationship with the environment, the whenua as expressed in the forests, the mountains, rivers and streams, all have a spiritual significance that some non-Maori find difficult to understand. Without a strong taha wairua linkage then the physical, the taha tinana, cannot be complete or fulfilled.

**te taha tinana** – this literally means the physical body. To comprehensively and sensitively understand care for Maori it becomes important to appreciate the facets of distinction that Maori have of tapu and noa. The head being tapu with bodily functions such as defaecation needing to be separated from it to maintain good health. Into this theme we also include the belief that the partaking of food removes the tapu of a given situation.

**te taha hinengaro** – this theme embodies both the mind and the body incorporating the capacity to think, feel and communicate. It is the sum of thoughts and feelings. The mind and body cannot be separated in any consideration of health and well being.

**te taha whanau** – taha whanau involves the capacity to care, to share and to belong, with individuals being part of wider social systems. For Maori the whanau is the prime support system that provides care and nurture, not only in the physical sense, but also culturally and emotionally. Interdependence, not independence, is the attitudinal state that is demonstrated in the Maori worldview of life and health. Aroha, literally translated in English as love, has a special relationship with whanau. In the context of whanau, aroha refers to the warm affection that members of the whanau feel for one another and this leads to the acts of caring that are performed by members of whanau, when adversity, sickness, or disability occurs to one of their own (Durie, 1998).

Good health of the whanau for Maori is dependent upon the balance of the concepts and influences that have already been referred to. These may be viewed as dimensions of health and other models of health such as that of Te Wheke (the Octopus), put forward by Rose Pere in 1984 adds to the dimensions already discussed with the concepts of mana ake, mauri, ha a Koro ma a Kui ma, whatumanawa, and waiora.

**mana ake** -- the unique qualities held by every individual and the whanau made up of those individuals.

**mauri** – is described as the life sustaining force that every one and every being possesses. It has also been described as the power of the Gods and Barlow (1991) states that it is mauri that makes it possible for everything to move and live. It is the mauri that binds the physical and spiritual together.

**ha a Koro ma a Kui ma** -- this is the breath of life that comes from the tipuna, and acknowledges that there needs to be a positive awareness of them to enable whanau health to be determined and maintained.

**whatumanawa** – this is the open, free and honest expression of emotion that is so necessary for a healthy individual. To laugh, to cry, to be depressed, to be overjoyed, are just some of the emotions that need to be expressed if the individual is to remain healthy.

**Waiora** – is the all encompassing health and well being of the individual and the whanau.

Without their attachment to the land, to the language, and to the family, the culture of the Maori would wither and die. This was recognised by the HFA (2000) who stated that: "explicit recognition of culture as a determinant of health is therefore an important component of effective strategy, policy and practice for Maori health gain and development in New Zealand's health sector" (p. 6).

## **He Anga Whakamana**

"He Anga Whakamana" (Ratima et al, 1995) contains the results of a study, part of which related to the Utilisation of Disability Support Services. Improved communication and information about such services was an issue that was

highlighted by interviewees. Also highlighted was the desire by many for a culturally appropriate model of service delivery (by Maori for Maori). This theme came through very strongly. The importance of whanau to the person with disability, and whanau involvement, was also emphasised by participants of this study when caregivers specifically were questioned.

A number of the recommendations from this report related to Maori service provision of health and disability services. They were timely, listened to, and had a large impact. I believe that these recommendations led directly to the establishment of the Maori Development Organisations – umbrella organisations that give positive encouragement, support, and enabled the development of Maori Service Providers of health and disability support services.

## **Maori and whanau**

Statistical definitions of 'Maori' have varied over time. Prior to the 1986 Census the definition was based on biological criteria that gave rise to the stigmatising statements such as "half cast", "quarter cast" and other statements relating to bloodlines. From 1986 the emphasis has been on ethnicity and ethnic identification. These changes have meant that long term trends and patterns need to be interpreted with caution (Statistics NZ, 1998). At the time of the 2001 Census 604,110 persons claimed Maori descent (18% of the total New Zealand population) but only 526,281 claimed Maori ethnicity.

The MOH (1998) adopted Strategic Result Areas for the Public Health Sector 1997-2000 that identified the need for health and disability services with a particular emphasis on whanau wellbeing and health. Recognition of the relevance of Te Tiriti o Waitangi to the issues of health and disability was demonstrated in these Strategic Result Areas with a focus on enhancing and improving the design, access to, delivery and monitoring of policies and programmes, all which impacted on Maori economic opportunity and social outcomes. Policy development was to be aimed at an effective health sector response which would advance health gain for Maori and thereby whanau.

The MOH (1998) report *Whaia Te Whanaungatanga* reminds us that: "Social policies often directly or indirectly impact on whanau wellbeing and health". In developing such policies there were six principles that policy makers needed to consider in developing policy with implications for whanau health. These were:

1. whanau wellbeing is pivotal to the wellbeing of Maori people.

2. the recognition and upholding of Te Tiriti o Waitangi is fundamental to the wellbeing of whanau.
3. whanau wellbeing is affected by all aspects of the economic, political, social and cultural position of its members individually and collectively.
4. whanau wellbeing is dependent on the social and cultural values and beliefs of the whanau being respected and valued.
5. whanau is the most direct source of support and encouragement which contributes to the wellbeing of its members.
6. whanau experience diverse realities and operate in a range of settings which must be recognised during policy, programme and service development processes (pp. 28-29).

It is also noted that there are four principles that underpin the operation of the health sector with specific application to the health and wellbeing of the whanau, and these are:

- services are organised around patients and communities, not health professionals
- local solutions to local problems
- ensuing better relationships between those who provide public health services
- decisions about resources need to be made as close to the need as possible. (MOH, 1998.)

The living arrangements of Maori also reflect the traditional importance of the whanau or extended family. Maori are reported to be considerably more likely than non-Maori to live in extended families, in households occupied by more than one family, and in large households (Statistics NZ, 1998).

Durie (2001) has defined the whanau as more than just an extended family. He states that it is a diffuse unit, based upon common whakapapa and within which certain responsibilities and obligations are maintained. Durie also acknowledges that the term whanau has been broadened in more recent times to include a number of non-traditional situations where Maori with similar interests, but not direct blood relationships, form a cohesive group.

Metge (1995) identified both whakapapa and contemporary definitions of whanau. These were:

- a set of siblings but not their parents
- all the descendents of a relatively recent named ancestor traced through both male and female links regardless of whether they act or interact together
- those descendants of a relatively recent ancestor who act and interact together on an ongoing basis
- a descent core group with the addition of members' spouses and children adopted, a collection of individuals and parent-child families who act and interact with each other on an ongoing basis under a common name
- descent groups of greater genealogical depth, namely hapu and iwi.

(pp. 52-53).

There have been a number of interpretations as to the functions of the whanau. Smith, G (1995) discusses the cultural properties of whanau; Durie (2001) the primary functions of whanau; and Metge (1995) also discusses the primary functions of whanau.

Durie (2001) states that there are five major or primary needs that are satisfied by the whanau. These are:

- Manaakitanga: the roles of protection and nurturing
- Tohatohatia: the capacity of the whanau and the family to share resources
- pupuri taonga: the role of guardianship in relation to family/whanau physical and human resources and knowledge
- whakamana: the ability of the family/whanau to enable members
- whakatakato tikaanga: the ability of whanau to plan for future necessities.

(pp. 200-202)

Metge (1995) also describes five primary functions of whanau, these being:

- to provide support and aid to members
- to provide care and upbringing for the children of members

- to provide care and management of group property
- to organise hui
- to deal with internal problems and conflicts.

(pp. 66-72)

The traditional whanau as described by Metge (1995) as a descent group based on a common whakapapa is a social and cultural structure for Maori. It is the primary source of identity, confidence and pride, and has the ability to assume responsibilities on behalf of its members, and to assign responsibilities for them. At the same time the whanau has the apparent conflict of being an environment for nurturing, support, protection and safety, while on the other hand being a source of censure, discipline, organisation and strength on the other. Above all else the whanau has retained the ability to be a source of support, protection and safety for Maori despite adverse factors, including socio-economic influences (MOH, 1998). It is this traditional descent group and its functions that was seen in the whanau groups that participated in this study.

Aspects of disability as they affect the whanau are drawn from data of the 1996 Census and the public health document "Whaia Te Whanaungatanga: Oranga Whanau" (MOH, 1998). The reader is reminded that there are individual, social and community determinants that influence health outcomes for whanau living with disability. Of the 20% of the total population that reported living with disability, 19 percent were Maori. "Whaia Te Whanaungatanga: Oranga Whanau" (MOH, 1998) also referred to the particular issues for whanau caring for others who are living with a disability. One of the submissions to the authors of this Report (MOH, 1998) stated that there was a problem of employing whanau members as the principal caregivers. The then current disability support service provision, believed that whanau support was expected to be provided without any cost. For paid care the client was expected to look outside the whanau and may have set up the possibility of care being culturally unsafe. It was felt that this attitude to whanau members actually reduced the whanau wellbeing and did not acknowledge the holistic approach of Maori to wellness (MOH, 1998).

The WHO (1991) has spoken on the issue of the cultural appropriateness of services and this is recognised as a problem for health care delivery to Maori. With the exception of services designed specifically by, and for Maori, the health and disability services providing care to Maori tend to be owned, controlled, managed and staffed by non-Maori (MOH, 1998). The support of the Maori Development Organisations (MDO) has seen a reduction in health and disability

service delivery in some areas being delivered to Maori by non-Maori service providers.

The development of MDO's gained much impetus, if not their origin, in the 1997 consultation process undertaken by the Public Health Group of the MOH. It is understood that this report was used as a guide to implement the new National/New Zealand First Coalition Government's agreement on health. Themes that were identified in this agreement that would go some way to meeting Maori needs were contained in the MOH (1998) report. These were:

- rangitiratanga – as a way of recognising Te Tiriti o Waitangi, Maori aspirations for autonomy and self-sufficiency and development of services managed by Maori
- access to quality mainstream services – whereby services are 'safe, equitable, culturally effective and appropriate'
- new and existing Maori providers – so that services are provided by 'not for profit Maori providers'
- gains and outcomes – 'keeping Maori health and independence a priority'
- aukiti –prevention/promotion – recognising 'disease prevention and health promotion give the best opportunities for significant long-term Maori health and independence gains'
- tikanga Maori and kaupapa Maori – including 'traditional healing and other services rooted in Maori health and wellbeing philosophies'
- integration – intrasectoral and intersectoral – recognising 'gains in health and independence stem as much from socio-economic advancement as improved health and disability services'
- resourcing Maori health and independence gains – including 'identifying specific Maori development funding, shifting resources from the margin to the Maori health and independence gain priority area, and ensuring the funder has strong partnership and participation strategies'
  - awatea – Maori development – meaning 'a holistic approach putting Maori health and independence improvement in the context of overall Maori development'.

(p. 33)

A whanau focussed approach is recognised as being effective in addressing the cultural barriers to whanau accessing health services (MOH, 1998). Programmes which are identifiably Maori, and which validate whanau and their values and beliefs, minimise the structural barriers that some whanau experience in the delivery of programmes and services.

The influence of the cultural bonds that both providers and whanau bring when interfacing in the health sector is recognised by culturally effective services. Culturally effective services recognise diverse whanau realities and are sufficiently familiar with Maori cultural values, beliefs and norms that impact on health practices and lifestyle choices and behaviour. This is necessary to eliminate the risk of inappropriate practices, which cause offence, create barriers of access and marginalize participation on cultural grounds. It necessitates providers being aware of the different power relationships between providers and consumers in the health sector, and the potential for providers to impose their cultural beliefs on whanau service users (MOH, 1998).

Having examined some of the issues related to health and disability service delivery; the effectiveness of these for Maori generally and whanau in particular; and the considerations that would need to be made to ensure the cultural appropriateness of such services, in the next section an overview of the Maori population of Taranaki is given.

### **Taranaki Maori – a profile**

Taranaki is one of the smallest regions in New Zealand in land area, totalling 7273 square kilometres.

The Census collects data on Iwi and ethnicity as two separate questions. The Iwi data comes from the question that asks if the respondent has Maori descent and if the answer is yes then they are asked about their Iwi allegiance. The results of the 2001 Census had 604,110 claiming Maori descent but only 526,281 claiming Maori ethnicity. It was also noted that 5,300 claimed ethnicity but not descent (Statistics NZ, 2002). At the time of the 2001 Census the total Taranaki population was 102,858 with the Maori population (by claimed affiliation) being 14,562. Taranaki Maori as a percentage of the Taranaki population totalled 14.1%. 55.7% were under the age of 25 years, 13.2% were adults aged 45-65, and only 3.8% classified as "elderly Maori", i.e.: over the age of 65 years (Statistics NZ, 2002).

There are eight Iwi claiming tangata whenua status in Taranaki and of these Te Atiawa was identified as the largest at the time of the 2001 Census. There is a matter of Iwi identification whereby some Maori who would be included in the numbers of Ngati Ruanui identify themselves as the separate Iwi of Tangahoe and Pakakohi (Table 5 and Figure 6).



**Table 5:** Taranaki Iwi numbers according to Census declarations 2001

<b>IWI</b>	<b>TOTAL TARANAKI REGION</b>	<b>TOTAL NORTH ISLAND</b>	<b>TOTAL NEW ZEALAND</b>
Taranaki – not further defined	72	339	369
Taranaki	1443	5289	5940
Te Atiawa	2238	8790	10,152
Ngati Maru	150	546	597
Ngati Mutunga	342	885	1206
Nga Rauru	564	2790	3087
Nga Ruahine	1308	3033	3228
Ngati Tama	189	699	777
Ngati Ruanui	1338	4779	5283
<i>Tangahoe</i>	81	243	261
<i>Pakakohi</i>	153	384	405

Source: Statistics Department, 2001 Census figures

I have related the considerations that needed to be made for a non-Maori to undertake research with Maori. Great care was taken to ensure that all safeguards were in place to protect the cultural and intellectual property rights of the Taranaki Maori involved in this study. This was achieved through the negotiated partnership that was developed between Tui Ora Ltd, Te Whare Punanga Korero, Makere Wano, Ngati Ruanui and myself.

The epidemiology of stroke that makes it an issue of concern in health care in Aotearoa/New Zealand, and the hugely inverse ratio of Maori to non-Maori affected by this condition has been outlined. The legacy of the health reforms that have affected the way health and disability services are delivered in Aotearoa/New Zealand and Taranaki in particular have also been described. The research design and method used in conducting the study are addressed in the next chapter.

## CHAPTER FIVE

### RESEARCH DESIGN AND METHOD

#### Introduction

It is clear that the incidence of stroke occurs at a younger age in the Maori person than the European/New Zealander (MOH, 1999a). However a review of the literature as published by the Ministry of Health, Te Puna Kokiri, and the School of Maori Studies, Massey University shows that the whanau experience of caring for members with disability from stroke does not appear to have been studied before. With the projected increase in the numbers of the total Maori population over age 65 (Statistics NZ, 1998, 2003) this study is considered to be a timely event.

It was considered that a qualitative descriptive study using whanau based focus groups and key informant interviews would best met the oral traditions of Maori. This would enable the collection of the lived experience of whanau members who had a member affected by stroke and enable rich descriptive data to be obtained.

#### Focus groups and key informants

A focus group has been defined as a collection of people working together on a particular issue. They have given their consent to be involved and have been deliberately invited for their knowledge in the area to which the research relates (Roberts & Taylor, 2002, p. 387).

Focus groups have become an important method of conducting qualitative research. Focus groups have as their objective the acquisition of information based on the perceptions, beliefs, traditions and values of its participants. As a consequence, focus groups are particularly well suited for conducting research among minority and other vulnerable populations (Calderon, 2000).

There are a number of cited advantages of focus groups that are applicable to this study. It has been argued that interaction is a crucial feature of focus groups because the interaction between participants highlights their view of the world and their values and beliefs about a situation. This is what I was endeavouring to discover – the whanau experience of caring for members with disability from stroke. Kitzinger (1994) states that an additional advantage of participant

interaction is that participants are able to ask questions of one another, as well as to re-evaluate and reconsider their own understandings of their specific experiences. This may in fact have never occurred in any meaningful way among members of the whanau.

The recommended number of participants in a focus group is variously stated to be between 6 and 10 (Easton, 1999; Lucasey, 2000; Morse, 1998). This is based on allowing each participant time to articulate their thoughts, experiences, and beliefs and understandings of a situation. A two hour session with 10 people would only give 12 minutes each to speak if equal time was allotted to each participant, therefore the smaller the number the more time the participant has to speak and it is hoped the more meaningful the experiences related.

The primary requirements that I believed to be important for the venue of the focus groups were that it was comfortable and accessible to the whanau. The choice of the venue for the focus groups was to be decided by the whanau although I would require the acoustics to be such that a clear audio recording of the discussions would result.

It was envisaged that the key informant would be the lead caregiver of the whanau member affected by stroke disability. The key informant was to be interviewed following the availability of the transcript from the focus group. The use of key informants at this time was seen as relevant to the definitive analysis of the data as these interviews would provide a clarification of issues that may have arisen during the focus group interview. The key informant might also provide more in depth meaning to other issues that may have arisen during the interviews. This key informant interview was to be unstructured. The key informant, by the very nature of their position as lead caregiver would have a unique perspective to offer upon the effects of the stroke on the whanau and the details of their caring for the whanau member so affected.

## **Preparation for, and initiation of the Study**

In achieving a negotiated partnership so that the designing and progressing of the proposed study might proceed there were a number of items that that needed to be kept to the fore:

- The principles embodied in Te Tiriti o Waitangi, of Partnership, Participation and Protection was to be incorporated throughout the design, development, implementation and analysis of the study. The

development of "Evaluating Research in Relationship to the Principles of Te Tiriti o Waitangi" Table 1 ensured the incorporation of these principles.

- The study needed to be culturally relevant, that is it had to have some potential benefit to local Maori. This was a study seeking specific information related to the whanau and their stroke experience. The study therefore had to be developed in terms of the Principles of Te Tiriti o Waitangi as outlined in Table 1 and only then would the findings be relevant to Maori, ie: be culturally relevant. This component was fulfilled for me with the stated ideal that the study might yield information that would enrich the experience of the whanau caring for a member with stroke.
- As the study was to take place in Taranaki there was a need for an awareness of Taranaki tikanga Maori and to this end the advice of Makere Wano who was my lead adviser was paramount. The design of the study reflects her advice and recommendations to suit the Taranaki situation.
- The intellectual and cultural property rights of local Taranaki Maori were to be respected and honoured at all times. This was a prominent part of the planning for the study with a partnership with Tui Ora Limited, the local Maori Development Organisation, entered into. Tui Ora Ltd would oversee the study and be the ultimate repository of all field notes, data, transcripts and audiotapes from the study.
- The study, whilst being a descriptive qualitative study would satisfy the academic requirements of academic rigor (and result in the awarding of a Masterate degree).

I was aware that I needed Maori approval, assistance, guidance, and blessing, to be able to proceed with the study I wished to undertake. In late 2001 I sought a meeting with kuia Makere Wano and Bev Gibson, Deputy Chief Executive Officer from Tui Ora Ltd, to discuss the proposed study and to begin the planning processes. I met with Makere Wano and Bev Gibson, to discuss the overall subject that I wished to explore in the study. Gaining a broad approval of my plans enabled definitive planning and production of a research proposal draft.

My proposed design was initially faulted by my Massey University supervisors and under their direction rewritten with a different approach to be utilised. I had initially proposed a more orthodox ethnographic design. I was advised that this method would not be suitable for the Aims of the study and that I should consider focus groups and key informant interviews. I kept my Maori research whanau support persons informed of these developments as I went through three drafts and finally obtained approval of my proposal. The Taranaki Regional Ethics Committee (TREC) did not approve the initial filing, requiring changes to design and consultation with an unknown (to me at that time) Maori iwi group, Te Whare Punanga Korero (TWPK). The TREC informed me that "this organisation brings together six of the eight Taranaki iwi to consider health issues for Maori and has a role in any research on Maori which occurs here" (personal communication, April 23, 2002). These iwi were Ngati Mutuanga, Ngati Tama, Te Atiawa, Ngati Maru, Taranaki and Nga Rauru.

(Subsequent to the commencement of the study, a seventh Iwi, Nga Ruahine, joined Te Whare Punanga Korero, leaving only Ngati Ruanui of the eight Taranaki Iwi to stand alone on issues of health.)

I met with John Glass, clinical psychologist and member of TREC to discuss their concerns as to study design. These concerns related to the criteria to be used in choosing the families to take part, and was I to look at the group of people who were not using services? There was not a great deal to change and I readily conceded the points he made. A meeting attended by John, the chair of the Ethics committee and the secretary of TWPK, also a member of TREC, resulted in final approval being granted for my study to proceed. Following these final amendments, the application as approved by TREC was forwarded to the Massey Human Ethics Committee along with copies of my correspondence with TREC. I was notified of their approval of my proposal (Appendix 2) after their deliberations.

An experienced research transcriber was identified for me. After agreeing to type up the audiotapes for me, she signed a confidentiality agreement and agreed on a fee for service.

With Makere Wano as my key support person I attended a hui with Te Whare Punanga Korero. There were representatives including kaumatua and kuia of six of the eight Taranaki Iwi present. I was formally welcomed according to tikanga by the kaumatua, and Makere replied on my behalf, and introduced me to the iwi representatives. A robust question and answer period followed between the iwi

representatives and myself. This hui resulted in approval for me to proceed with my study.

I had discussed in depth with Makere and gone through the actions and steps that I envisaged would occur when the study got underway. She endorsed my proposals as "safe" and within the tikanga of Taranaki Maori. (Taranaki in this context is the provincial land area and not the actual Iwi.) I asked for and she undertook to have a mihi written for me in Te Reo for my use at future hui.

Two days later following up another recommended contact I met with Ramona Rongonui of the He Whakaruruhau Trust. A paraplegic she fulfils the position of Disability Services Advocate for Maori of Taranaki. To put the work of the Maori Disabilities Advocate into context with the hospital provided services it should be explained that the Taranaki District Health Board does not employ her. The He Whakaruruhau Trust is a specialist Maori based service provider contracted to Tui Ora Ltd. Her area of responsibility is to cover the whole of Taranaki.

A wonderful, open, spontaneous woman, she welcomed my proposed study, particularly the steps I had taken in its design to protect and safeguard the interests of Maori. I gained her immediate support for the study and her willingness to assist in identifying whanau groups to approach. She undertook to do this for the study and to lead the introduction hui.

With Makere and Ramona leading my research support whanau, the study was ready to begin. My first introductory whanau hui was arranged very quickly in Stratford where a whanau wanted to join the study and were most keen that their story should be told. This immediately raised a procedural problem of tikanga for me as Stratford was within the Iwi boundaries of Ngati Ruanui. Through the blessings of TWPK I could proceed elsewhere in Taranaki but not in this part of South Taranaki without the blessings and permission of Ngati Ruanui.

I immediately made contact with the Chief Executive of Ngati Ruanui Tahua Iwi Authority, Spencer Carr. A hui was held, attended by a number of the senior kuia and kaumatua of Ngati Ruanui and in particular by Suzanne Carr, the Manager of the Ngati Ruanui Health Service. I was accompanied by one of my research whanau kaumatua, Matua Barry who ensured that appropriate tikanga was followed.

Following an explanation of my proposed study, an extensive question and answer period followed. It was apparent that the excesses and abuses of tauiwai

researchers involved with Maori had been the experience of this Iwi with a number of unfulfilled promises and guarantees being the legacy I had to face and overcome. With the support of my kaumatua and my open and honest approach to all questions, including an examination of the study design where upon all control of my study was vested in Maori, I achieved the blessing and full support of Ngati Ruanui to proceed with my study in their tribal area. Suzanne undertook to become part of my research whanau as contact for the Iwi. With this approval I was now able to enrol the Stratford whanau into the study.

As the study proceeded Makere or Ramona made initial contact with whanau. The study was explained and the whanau was asked if they would meet with me. At this meeting we were always accompanied by a kaumatua, who gave the formal blessings to our korero. I received a 100% agreement to participate at all these introductory meetings. A date was then arranged and I returned accompanied by either Makere or Ramona, and most times with a kaumatua to undertake the focus group interview.

It had been my intention that either Makere or Ramona would fill the role of Moderator with myself sitting quietly in the background, however I was asked by every whanau group to lead the discussion at every focus group held. This development took me by surprise as I had thought that the whanau groups would be most comfortable and therefore more likely to relate their stories to another Maori. However it was an indication of the respect held for the members of my research whanau by the members of the whanau to be interviewed that they all stated on every occasion that if I had Makere or Ramona's support, then I would have theirs too. There was possibly also an element of: 'he kanohi kitea' – 'a face seen is an argument understood.' This whakatauki illustrates the fact that making a request in person is considered more courteous, more understandable, and therefore more likely to obtain a positive outcome for the individual.

Following the recording of the focus group interview the tape was returned to the Information Technology Dept of the Western Institute of Technology at Taranaki where a CD-Rom copy was made. The tape was then passed onto the typist who transcribed the tape and returned it to me with a hard copy transcript and a computer floppy disc of the transcription.

## **Ethical Considerations**

An Information Sheet (Appendix 3) was prepared and used by my whanau contacts, Makere Wano and Ramona Rongonui, when they made the initial contact with potential whanau study participants. Consent forms were available in both Te Reo and English (Appendix 4 and 5) but in actuality were never required. Following Maori oral tradition a korero where the whanau had the study explained to them and any and all questions answered, inevitably led to the whanau giving consensual agreement to participate to the kaumatua who was present. This was considered a full and sufficient consent process and was in keeping with the Maori oral tradition.

It was acknowledged that the focus group interviews might expose some whanau to unresolved emotional responses dating from the time of, and possibly through, the stroke event. There was an acknowledged responsibility to deal with this if it occurred and to this end appropriately experienced Maori social workers were available to the research whanau if required. Thankfully, although there was one particularly difficult memory journey for a whanau as they recounted their tale, this assistance was not required.

An unexpected ethical consideration arose during one focus group interview that related to the caregiver not having been informed of a service that would have greatly assisted her in facilitating her husband's rehabilitation. Throughout the study I was conscious of my rehabilitation best practice clinical background and strove at all times to prevent this from causing me to prejudge or possibly altering the whanau experience of stroke by an intervention of mine. I was aware that any comment or action of mine could influence the whanau experiences and their reflection on these. With my knowledge of the services and caregiver entitlements, I could not ignore this service provision deficit. By good fortune the research whanau person this day was the Maori Disability Support Advocate who was able to immediately write a referral to the service concerned so that the deficit might be rectified. This incidence alerted me to the potential of future deficits that might need to be attended to for the betterment of the whanau caring for their member affected by stroke.

A final ethical consideration, which needed to be discussed with participant whanau, was that although anonymity of the participants was guaranteed and no names were to be referred to in the subsequent written thesis, due to the smallness of the Taranaki Maori community individual participants and whanau groups would be identified merely by the relating of their story. This was

acknowledged as being inevitable and unavoidable however the commitment to the study was confirmed by all participants and by members of my research whanau.

## **Whanau Participant Profiles**

A total of seven whanau groups were enrolled in the study. The seven whanau groups involved in this study would fit within the third and fourth traditional definitions as defined by Metge (1995) (see Chapter Four) as a descent core group who act and interact together. Only one group did not have tamariki or mokopuna actually living with them.

The first whanau was made up of a husband, wife, tamariki and mokopuna. Whilst all the whanau experiences were unique and offered different perspectives this was particularly so with this whanau as the husband had the actual stroke whilst visiting whanau in Australia. The Australian hospital experience of the wife contrasts with the New Zealand hospital experiences when she succeeded in having her husband returned home.

The second whanau group was the only South Taranaki whanau group enrolled in the study. The wife found her husband still in bed rather than at work. He was always away to work before she arose in the morning. The lack of support services in rural New Zealand is highlighted in this tale.

The third whanau group was that of a family of young high school age children at home and where the father played an extremely supportive role with his children and mokopunas. He was taken ill at work and the wife rung to go to the hospital.

The fourth whanau group had an experience where their wife and mother who was so affected by the stroke, she was taken home to die with the agreement of the hospital staff. To see her walking, talking and taking a full role in her whanau today is an overwhelming experience. Their tale truly affirms the interrelationships of the holistic and integrative nature of Maori health.

The fifth whanau group involved only the husband and wife and a female relative. In this situation the wife knew what was happening to her as she suffered her stroke event and she clearly remembers fighting the onset of the physical symptoms as they occurred.

The sixth whanau group involved the husband who was actively running his farm and playing bowls. Still living on the farm, their tale has much to offer in consideration of the work and worth of the whanau member so affected who was the lead decision maker prior to the stroke event. Living under the shadow of Pukerangiora (Appendix One) this whanau demonstrated a lived commitment to the wairua forces in their lives.

The final whanau group involved a mother now living with her daughter and son-in-law. Unable to speak, and with her husband alive at the time, the whanau cared for their mother (and still do).

Preconceptions I held as to the extent and scope of the whanau were not upheld as these focus groups occurred. This preconception arose from a stereotypical view of the whanau being a large extended family. I had envisaged focus groups of at least 4 to 6 participants and probably more, however although some reached 4 and one of 5, the majority consisted only of the husband and wife with a kaumatua and kuia or Maori health professional present. In some cases I was informed that there were immediate members of the whanau that had chosen not to take part and that wish was respected. Other members of the whanau were living in other parts of New Zealand or overseas, and while the study was discussed with them, it was not possible for them to return to the family to participate. I am not alone in thinking that the whanau would be a greater rather than lesser number of persons. Statistics NZ (1998) states that Maori are more likely than non-Maori to live in extended households occupied by more than one family and in large households (p. 10).

## **The Interviews**

It was intended that the focus group interviews would be totally unstructured with only the minimum of direction given by the moderator. All korero/hui gatherings were begun with a karakia at an appropriate time after general everyday conversation regarding family members, mokopunas, health, the weather, and other subjects. Following this karakia the question was posed: "Was there anything that led up to the stroke?" or: "What do you recall of the events that led up to the stroke?" Conversation then flowed with much dialogue and interchange between whanau members, all conversation being audio recorded. An appropriately phrased question was asked following these disclosures from whanau members as the experience of the hospital experience was elicited and on into the initial discharge home experiences of whanau and

patient. I concluded the interviews with a general question along the lines of: "What would you say to some other whanau experiencing stroke?"

It had been intended to follow up the focus group interviews with a key informant interview however due to the small numbers involved in the focus groups only the first two lead caregivers of whanau groups interviewed were required to participate in this clarification process. A third key informant interview was made necessary as the tape recorder had malfunctioned during the focus group interview and much of the data had been lost. The key informant interview allowed this data to be recovered.

### **Checking of transcripts**

Only half of the whanau groups requested a copy of the transcript for checking, and subsequent alteration or deletion of sections was offered in the pre interview discussions and explanations of the process of interview. I believe it was significant that not one wanted any changes made. One lead care giver waved away the offer to return the transcript to them with the comment: "No don't bother." This comment was immediately supported by another of that whanau who said: "It's all in our heads."

### **Analysis of content of transcripts**

Manual thematic analysis was undertaken on the data obtained, rather than using computer assisted means. As the transcripts were read the Aims of the Study were kept before me on the wall in front of the desk where I worked. This was done to ensure the themes would be recognised as they arose and that I would not be sidetracked by the possibility of side issues arising from the data.

As the transcripts were read initial notes were made in the margins opposite key paragraphs and statements. There was much solid descriptive data presented from the interviews such that the rigor of qualitative analysis was apparent. This was something actively sought by myself from my research whanau support persons.

The main themes coming through from reading the transcripts were the broad categories of "whanau", "services", "information", and "spirituality". Specific words relating to these themes were easily identified and explicit. I was also mindful of implicit themes that appeared during the relating of the story of the

whanau experience, usually by innuendo or a hint that supported the explicit themes identified. As the explicit themes were identified the transcripts were read and reread to ensure that they were an accurate reflection of the stories told. The implicit themes that arose were able to be placed to support the explicit themes.

The actual method used to undertake the data analysis was as follows: Each transcript was printed in hard copy on a different coloured paper. Each transcript was cut into sections of text connected to a theme and placed in a specific pile on the table. These piles were reviewed and merged until the broad themes of whanau, service provision and deficit, information and spirituality were identified.

I decided to use the qualitative evaluative criteria put forward by Leininger to evaluate the findings of my research and the process of that research, as it was critically important that the Maori worldview was expressed in the definitive findings of my research. The actions of Bev Gibson of Tui Ora Ltd, and the subsequent involvement of Makere Wano, Matua Barry, Matua Toni, and the kaumatua of Ngati Ruanui, in this process to review and critique my data analysis and findings I believed would fulfil these criteria as outlined by Leininger.

The six "central and important criteria" developed by Leininger to evaluate qualitative data are :

- Credibility
- Confirmability
- Meaning-in-context
- Recurrent patterning
- Saturation
- Transferability.

(Morse, 1994, pp. 105-107).

Credibility, or the truth, value or believability of the findings is a given as the lived-through experiences of the participants could not be doubted. With kaumatua and kuia present as the interviews were recorded, the sincerity of the emotions of the participants, and expressions of goodwill with "our story must be told" statements from them, all added veracity to the credibility of the data so collected. The research whanau on reviewing the transcripts were in agreement with the themes that had been identified.

It was a considerable advantage for me to be steeped in the importance of taha Maori tradition and local tikanga and beliefs. The Taranaki region has a proud history of settlement by eight Iwi long before the settlement of the European and the resultant Maori wars that resulted in land being lost was the base for grievances that are still being worked through today.

In retrospect I am extremely grateful for two influences in my life as I grew from childhood to adulthood. The first of these was the influence of growing up next door to Aunty Marge, respected elder kuia of the Taranaki peoples. As I went to school with her children (Marama and Henry) and experienced tangi and other ceremonial events, by a process of osmosis I gained insights into the depth and wonder of Maori culture.

The second significant influence in my life was that of a step grandfather, one August Voullaire. French by ancestry, he was actively involved with the local historical society and had a wealth of knowledge regarding the beliefs and values of Taranaki Maori and the events of European settlement. As I grew up, from these two influences I learned the history of places and events such as Parihaka, the Omata Stockade, and Pukerangiora.

The result of these influences on my life made the experiences of the participants totally credible, particularly when they tied events into their taha Maori or wairua influences and beliefs. With verification from the research whanau experiences, the Maori worldview was expressed in the conclusions drawn as the results of the study were written up.

Confirmability, or the repeated direct participatory evidence obtained from the participants, gave confirmation to the experience being remembered and related, as what was said in one interview was often repeated by another participant in the same interview, or frequently, in another separate focus group interview. The key informant interviews that were held only verified the evidence of the findings of the researcher and added to the criteria of confirmability to the data analysis.

Meaning-in-context with reference to the data collected in this study had special meaning as some of the participants explored their taha Maori or taha wairua of their lived experiences through the stroke incidence. The situations and lived experiences they related could only be understood and accepted in these terms and understandings. These were significant experiences for the participant and

they became shared and moving experiences for myself and others involved in a particular focus group interview. The concepts of Insider/Outsider team research as described by Bartunek and Louis (1996) began to be highlighted in these experiences and were further elaborated upon when analysis took place with the research whanau giving te ao Maori point of view of a particular related occurrence.

Recurrent patterning is the term Leininger uses to refer to repeated sequences of events, experiences, or events that tend to be repeated over time in designated ways although the event can be repeated in different or similar contexts. The identified patterns of sequenced behaviour and expressions and actions by whanau over a period of time as they progressed through the stroke incident gave credence and credibility to these criteria. Whilst the actual experience was different between whanau, the occurrence of it followed the same sequence of events during the whanau stroke experience.

Saturation is a commonly used term by those who critique research. In its application to qualitative research it refers to the situation where the researcher is unable to find any further explanation, interpretation or description of the phenomena being studied. Towards the end of some focus group interviews that were held there were comments from the participants that indicated saturation had been reached with statements such as: "I have told you all that there is to be told". This was always with the comment at some place in the interview of "Our story must be told."

Leininger talks about transferability as the term that refers to whether or not the particular findings from a particular qualitative study can be transferred to a similar context or situation. The intention of this study was not to produce generalisations but an in depth understanding of the whanau experience of stroke as experienced by Taranaki Maori for the future benefit of Taranaki whanau experiencing a stroke incident. I would not like the findings of this study to be generalised across all whanau groups experiencing stroke, as this would devalue the experience of the participant whanau. It would also be inappropriate due to differing service delivery of services between differing DHB areas. One must always remember that Maori are not a homogenous group and that findings in one iwi, hapu, whanau may well not be extrapolated to another iwi, hapu, whanau. I believe that the whanau in country areas have a different experience to the whanau in urban areas and that the numbers of whanau and age ranges all have, and do play, a considerable part in shaping the experience of the stroke incidence. The criteria of transferability will be used by Taranaki

Maori to afford lessons for future Taranaki whanau experiencing stroke based upon the findings of the whanau related in this study. This will be an appropriate use of the findings of the study.

## CHAPTER SIX

### THE WHANAU EXPERIENCE OF STROKE

For the whanau and individual member of the whanau that had experienced a stroke event there were three distinct central times. These were:

- a) experiences leading up to and around the actual event of stroke;
- b) experiences around the hospitalisation of the whanau member affected by stroke; and
- c) experiences around being at home from the immediacy of post discharge from hospital through to the present day.

There were unique and quite distinctive experiences within these central times for the individual whanau member affected by stroke and the individuals who made up the whanau. Some of these related experiences are probably no different than those of non-Maori and their families, however the underlying importance of the collective of the whanau, its strengths, supports, and caring, are clearly identified in the telling of these experiences by the whanau members.

It needs to be acknowledged that the hospital experience of stroke will, and does, vary between different District Health Boards throughout Aotearoa/New Zealand irrespective of ethnicity, however in this locality this thesis talks exclusively of the Maori experience in Taranaki. The hospital experiences as relayed to me all occurred within the same hospital except for one that began in Australia.

The descriptive reflections of the onset of, and the effects of stroke in one member of the whanau will be explored in this chapter. The next chapter will endeavour to explore those items that are particular to Maori as revealed during the interviews and to provide an interpretive explanation of them. Chapter eight will bring all the points together in a concluding discussion.

#### **The experience of the onset of stroke**

In the days and months leading up to the stroke event some whanau members had a premonition that something was "not right" with their partner. Overall the premonition or "knowing" that something was wrong was a striking feature of the sensitivity and empathy that some partners had of their whanau member heading up to the actual stroke event.

*I didn't know it would be a stroke but I knew he wasn't quite what he used to be. [WG3, wife]*

*We sort of started worrying a bit, what was wrong, but she seemed to be quite well. [WG5, daughter]*

*Probably about six months, or it might have been a bit longer, before he actually had the stroke, he wasn't well, he just didn't feel well. So he'd go to the doctor and the doctor thought it was one thing, then he thought it was another thing, he thought it was gout, he thought it was something else, something else, it just went on and on. [WG6, wife]*

*The day that I saw it actually happen, I kept kicking myself, I should have said something when I first started noticing, maybe it would not have happened. But he was always going for medical check ups, so there was nothing picked up there that anything was wrong, and that's what I couldn't get over, how they never picked it up that there was something wrong.*

*I can go back two years before that when I started noticing. They never picked up that there was something wrong. But I took notice, and I've kept a diary for 47 years. [WG2, wife]*

In the first two accounts there was no specific reference to the involvement of health services prior to the stroke. However the wives of the whanau members affected by stroke in the third and fourth quotes stated that they knew that there was 'something wrong' with their husbands. One wife almost blames herself, as she believes with her meticulous diaring of everyday events over 47 years she could determine that her husband's health had started to show signs some two years earlier.

Immediately prior to the stroke event something occurred which must have been rather frightening for both wife and husband in the fourth quote. The wife related that:

*...we had a nice day like this...it was one of those days I stayed home, premonition sometimes makes me stay home. I just felt I needed to be home...I came here and looked and I saw him drive the tractor into the hay barn. That was fine, and then I was just sort of observing around the farm and I'm thinking 'wish you'd stop working'. Then I saw him walk out, take his jacket and throw it over his shoulders and walk to the corner*

*post. He looked like someone with a big load on his back, his feet were dragging. Then he walked across to the middle of the paddock. I thought: 'Oh, he must be going to check the gate, he must be going to let the cows in there'. Anyway, he stopped in the middle of the paddock...I saw him look around, look up here, look there, turn around and walk back to the middle post, but slow, and I thought: 'Oh, I think you need some help'...then I saw him in the corner leaning on the post and something told me he wasn't well. Gradually I saw him walk back here. So I went out to meet him but he was slow and he just followed the track but his head was down and he'd stop and I'd see him look around, and then I went out there. By the time I got down there he was starting to walk fast. I put my arm around him and I said: 'what's the matter?' He said: 'I can't see. I can't see'. I said: 'Come on, no more working for you'. I got him in here and all he wanted to do was lay down, so I helped him on to the couch and he lay down. A few minutes later he was asleep. Later on he got up and woke up and I said: 'Are you hungry?' He said: 'I'm thirsty'. So I gave him a lot to drink. He said: 'Hell, I don't know what's wrong with me. I feel bloody tired. I have just got no energy.' So I took his pulse and it worried me because it seemed to be fluttery. Then he went to sleep again and I said: 'I think I had better take you for a check up'. I did take him for a check up and they didn't pick anything up at the time, they didn't, all they said to me was that he was overworked and he needs to rest.*

[WG2, wife]

The stroke event occurred one week later.

*I heard this thump. He had gone to the toilet and his legs gave out under him. [WG2, wife]*

Her husband also understood clearly that something was wrong but did not know what or why and was equally puzzled as to why he had been unable to obtain any answers from the health service.

*I walked around the farm and wondered what the hell I was doing here. [WG2, stroke patient]*

With the other three whanau groups there was no warning, no indication, no premonition that something was wrong, prior to the stroke event. One wife reflecting on the experience quite graphically describes the puzzlement of it all:

*He had never been to hospital, ever, ever. You know on the (employment situation) they used to have those check ups, pass with flying colours. I*

*used to say How? Smoking cigarettes, go to the pub, you know Thursday pay night. Saturday down there taking the bets and watching the rugby, but work wise he was healthy enough to work. They never found anything.*

[WG1, wife]

The actual occurrence of stroke occurred at variable times and in variable places. Three persons had their stroke at home; one in hospital after admission for another acute reason; one at work; one on holiday in Australia; and one whilst enjoying a favourite activity of line dancing.

For the whanau members who were at home they were either present when the stroke occurred or found their loved one immediately following the event.

*I whipped back into the kitchen and I saw his lunch box still there and I didn't know, something in here (indicates her heart) told me then I heard this, it wasn't a wailing, it was like a calling out, and I just took one look at him, oh that was enough. I thought 'he's had a stroke.'* [WG1, wife]

This lady had a daughter at home able to assist her, although this took some prompting:

*I wanted someone to tell me what to do. I didn't panic. But my daughter did. She was more of a problem to me than he was.*

*I said: darling I haven't got time for you, just try and help mum. Go in by dad, go and sit there, stop that blubbing, go in there calmly and rub dad.* [WG1, wife]

That special empathy, that instinctive 'knowing' that was a remarkable feature in the stories of whanau became apparent as the wife of another whanau member recounted how she went to call her son to help her with her husband:

*I rang (son) but (son) was already coming down the hill with his cell phone. I said: 'where are you?' He said: 'I'm nearly there' and I said: 'Did someone ring you?' He said: 'Nobody I just feel there is something wrong.' I said: 'Yes get here quick.'* [WG2, wife]

This woman describes being on the 'verge of panic' but the imminent arrival of her son assisted her to regain control of herself. The son suggested to her that his father was having a stroke and that they should get him to the hospital. They called into the surgery of the local doctor who concurred with their

diagnosis and due to the distance for an ambulance to come to them told them to go on straight to the hospital while he (the GP) phoned ahead.

Other whanau were told by someone else, via telephone message, that their loved one had been admitted to hospital.

*It was August 13, about 10.30am that we got a phone call from the guys at work...he had been rushed to hospital. [WG3, wife]*

The assumption made by this woman was that her husband had had a heart attack, but when she saw him in the hospital she states that: "I knew it wasn't a heart attack but I didn't know what it was at the time."

For another whanau there was an acute admission to hospital as the wife and mother had an uncontrollable bleeding nose. Admission was considered necessary to bring this under control. It was some hours after this admission that the wife and mother was affected by a stroke event.

*...dad came in the evening and said: 'mum's in hospital.' I said: 'Oh what's wrong?' He said she had haemorrhaged. I went in with dad in the evening and mum was still conscious and then she slipped into a coma...[WG7, daughter]*

This whanau will always have questions prefaced with "if only..." as to the treatment of their wife and mother; questions which can never be answered.

Whilst a stroke event is nearly always unexpected, and certainly so with the physically well and active individual, for one couple it was a very unexplainable event. A very physically active couple, this whanau group of husband and wife were an inspiration to all who knew them. Actively running, both of them well into their 70's, the husband was at the gym and his wife participating in her weekly line dancing session when she had her stroke event. This woman took control in as much as she could and informed her friends to call an ambulance because she was having a stroke. As she was being taken to hospital by ambulance her husband was telephoned. He recalls:

*I had some fear when they said: (wife) has had a stroke and she's been rushed off to hospital. [WG4, husband]*

As a result of the very physically active lives they led, this husband and wife were very puzzled as to why the wife should have been affected by stroke.

The father and husband of another whanau flew to Perth to have a holiday with his tamariki and mokopunas. There was a family party on the Saturday night and one of the sons telephoned his mother on the Sunday night. He stated that he didn't know what was wrong with his father as he had been asleep all day. He blamed it on the 'booze'. Not accepting this and with a growing concern the wife asked to speak to her daughter. She (the wife) was alarmed as her husband was a diabetic and did not drink a lot anyway. Her first thoughts were of a diabetic state. The daughter was instructed to wake her father and give him his pills. When the daughter reported to mum that she couldn't wake her father the response was immediate:

*Ring an ambulance because there is something wrong...ring me from the hospital. I waited and waited. It must have been about four hours later (that) the doctor rung and told me he had had a massive stroke and it was touch and go at the time. (Australian experience) [WG6, wife]*

The experience of the stroke event as it affected the whanau members and the individual concerned are analysed and assessed further. This Australian experience of one whanau contrasts considerably with the New Zealand experiences and will be further recounted to provide an elaboration of the experience and contrast for the reader.

### **The partner faces the situation**

A striking feature for me was how the partner of the whanau member affected by stroke responded upon receiving the news of the stroke or admission to hospital. They not only seemed to be able to draw on some inner strength and hold themselves together irrespective of the inner turmoil they were suffering, they were able to hold it all together for the sake of the perceived need their partner had for them, and for those immediate members of the whanau they were responsible for.

*I was there within 24 hours then began the long haul. (Australian experience) [WG6, wife]*

"The long haul" – how accurately descriptive of the wife's experiences from that time to the present day. This wife is describing not only her initial response she had to being told of the occurrence of stroke but how the event changed her life and that of her whanau forever. Further elaboration is given at the appropriate place later in this chapter.

The sense of responsibility felt by another wife towards her husband, and the need to be with him is clearly expressed in the next statement:

*I had to basically face up to it and help settle him and make sure (husband) was OK and be with him all the time regardless...even then you don't know, you are not sure what is going on; its just all over your head but you have just got to cope day to day. [WG3, wife]*

Although there was an immediate responsibility felt towards the husband, the wider whanau was not forgotten and in the midst of the turmoil the tamariki and mokopuna were thought of. This wife was struggling to get some explanation of what was wrong with her husband and had felt rebuffed by the busyness of the doctor who would not stop and talk to her as to what was happening.

*Well I'm not going to let them do that to me, I'm not going to do this to him. Pull it together for the kids. They were all there and I had a friend go and pick up the two youngest ones from school. [WG3, wife]*

### **Staying with the whanau member in hospital**

In all but two of the cases of the whanau experiences that were relayed to me the immediate partner stayed either with the whanau member affected by stroke in their room or nearby in the hospital. This occurred as an expression of aroha and a need to be with their whanau member without regard for their own comfort or needs.

*I was there right through and he was in hospital for seven weeks and I was there for that seven weeks, I never left him. [WG2, wife]*

*I never left him by himself, ever, unless someone else was in there, for at least the first four weeks. [WG1, wife]*

Members of the whanau gathered to be with their member affected by stroke and were able to use the facilities available in the hospital. The whanau room is now found in larger Aotearoa/New Zealand hospitals. In the experiences that were retold at interview the availability of such facilities were very much appreciated and met the needs of the whanau to be able to be close to their whanau member.

*Gosh we lived at the hospital in the little marae up there. All the family were there and bringing food – it was like a marae, we treated it like a marae. [WG7, daughter]*

*From then on we stayed in that part where we could gather as a family.*

[WG1, wife]

A feature of the whanau actions during the hospitalisation experiences was the mutual support of one for another. This sharing of the work of caring, the grief, and the burdens of care are just some of the enabling effects that define whanau resilience in the face of a catastrophic event such as stroke. A good example of this sharing was noted in that the wife/partner was never left alone in the hospital. In a number of cases other whanau members, particularly children and mokopuna, supported the partner. In all cases this expression of caring began immediately – once they arrived at the hospital they did not leave.

*(Mokopuna), he would have been about 10, he decided to stay with me. He sat there in his sleeping bag and he was there.* [WG3, wife]

*Always one staying with me at the hospital.* [WG1, wife]

*Very, very supportive – a brother who went to the hospital every day. I'm talking two and a half months. He did not miss. (Australian experience)* [WG6, wife]

The staying of close whanau members at the hospital was common to all whanau groups. The gathering of other whanau members seemed to be an automatic occurrence. The understanding of the significance of the whanau to the patient enables most hospital staff in Aotearoa/New Zealand to accept larger numbers of family and visitors visiting the patient than normally occurs for non-Maori patients.

*She always had lots of visitors, lots of nieces, and (Kaumatua), and dad's side of the family as mum comes from a big family, so they always shared; there was not a day went by when she didn't have visitors.* [WG5, daughter]

*If anything I probably had too many visitors in one hit – 31 was a bit many (much laughter).* [WG4, stroke patient]

One partner was not offered the opportunity to stay with his wife, either at her bedside, or by utilising the whanau room facilities. Whether this was by oversight or a deliberate decision of the hospital ward staff is unknown.

*They let me see her all the time, but there was no suggestion, but I didn't even think to ask, can I stay? – 'you might as well go home'.* [WG4, husband]

The comment attributed to a ward staff member "you might as well go home" suggests that the hospital staff did not understand or did not consider this man's needs or wants to be with his wife through these immediate hours post admission.

The wife who flew to Australia to be with her husband had some observations to make as to the treatment of the needs of whanau (the cultural needs) in an Australian hospital.

*He was in a small room on his own, which was self contained, with a shower and all that, and there were two seats in there. A shower wheelchair and a plastic one. I slept on that for two days. Yeah they give you nothing aye, they don't give you nothing. (Australian experience) [WG6, wife]*

This wife had been told "it was touch and go." She had sped to be at her husband's side yet no facilities were in place to allow her to be with him. From the experience of caring for relatives in Aotearoa/New Zealand hospitals I have seen consideration of relatives needs made that range from lazy boy chairs being provided for an immediate family member to stay beside the patient; meals and wash/shower facilities being made available; through to full living accommodation as demonstrated with whanau room facilities. In this situation there appeared to have been no facilities for immediate relatives to stay with their loved one. With the lengthy travel required to get to Perth from within Australia, let alone from New Zealand, the experiences related by this wife appear to indicate a significant oversight in the provision of care for family of inpatients no matter who they were or where they were from.

The observation of Australian hospital staff conduct towards them that made the most impact on this whanau related to cultural safety and the needs of the whanau. In Aotearoa/New Zealand I believe most hospital ward staff now understand the principle of needing to care for the needs of the whanau because if we fail to meet these, often unexpressed needs, then we will ultimately fail to meet the needs of the patient.

*The hospital (Royal Perth) did not know how to care for relatives?*

*No. They were shocking*

*Can I have a cup of coffee? "No you're not allowed".*

*It was the same at the Rehab [sic] Hospital. Yeah, you were not allowed anything.*

*It wasn't only Maori, it was all cultures. There was an elderly Aborigine woman in there, but she was a white one out of a Pakeha, and they were having the same problems that I was having.*

*Talk to them about being cultural sensitive? They just wouldn't know what it means. Yeah [sic] so it wasn't just Maori, it was all races, everything was black and white. [WG6, wife]*

This is believed to be an accurate commentary on the attitudes of the staff of these Australian hospitals. The whanau members were compelled to stay by cultural imperative and practice with their member affected by stroke irrespective of the attitudes of staff or the obstacles put in their way. There were benefits for them as they learned the hands on care, the Activities of Daily Living personal cares of their loved one.

### **The whanau learns the hands on care**

The constant presence of whanau led to benefits for them in that they began to quickly be involved in the hands on physical care of their whanau member. This was a task that was certainly welcomed by whanau however there are subtle undertones detected from the relayed memories of the hospitalisation experiences whereby whanau were expected to undertake these cares simply because they were there.

*The first week was good because we were just watching and trying to fit in, trying not to be a nuisance to the staff who were trying to do their job, but I had taken note of a lot of things. [WG1, wife]*

This wife is recounting how just by being present she observed and learned the methods and techniques of giving personal cares to her husband. She makes a telling comment when she recounts how the whanau always were with her husband but how they always tried to not be a 'nuisance' to staff caring for him. Deficits in care were noted and attempts to correct the deficit without giving offence to hospital staff were undertaken:

*They said we weren't allowed to do it until we watched them do it. Well we let it go, let it go, he never got a wash that day...So what we did, we didn't turn dad but we made him fresh down there (indicates lower body). For dad these things are personal and dad is very very fussy like all old Maori people. So we changed him as much as we were allowed, and then we got some good staff on. [WG1, wife]*

This whanau resolved any further possibility of conflict and deficit of care by the younger son taking on the responsibility of giving daily personal cares to his father.

*My youngest son took over the actual hands on, but I was there.*  
[WG1, wife]

On some occasions the goodwill and willingness of whanau to share in the personal cares appeared to be taken for granted. At the very least it seems to have been assumed that as the wife had watched staff bed sponge her husband then she would now know what to do.

*I thought that paid off in the end because I would watch and they would say 'would you like to wash (husband)' and give me the things to wash him and helped out.* [WG3, wife]

The astute observations by this wife were demonstrated as she was able to wash her husband after being given the necessary equipment to do so yet there had never been any instruction in the techniques of assisting her husband with personal cares. She also knew some basic transfer skills without having being taught as she freely acknowledged:

*But his stay in hospital paid off because I knew how to transfer bed to bed or wheelchair, whatever, and shower him.* [WG3, wife]

There is an inherent danger in this learning by observation as whilst the personal cares and transfers were carried out efficiently and correctly according to accepted procedure there had been no instruction on techniques and safety issues related to these procedures and techniques. This leaves both the whanau member affected by stroke and the relative open to personal injury. A cursory examination would show that this was an unacceptable risk to the operational management of the hospital.

An element of modesty for their loved one and respect for the dignity and mana of the whanau member affected by stroke was graphically described in one interview:

*We bathed him and showered him because they said they would come in and bed bath him and oh no I couldn't stand that.* [WG1, wife]

It was respect for the perceived feelings of the husband and father that drove these members of the whanau to undertake the personal cares. Another whanau also expressed similar concerns for the dignity and self respect of their whanau

member affected by stroke. In this case the whanau member affected by stroke was female:

*It was awful one day I was a bit late coming to the hospital. She was sitting there. I don't think her hair had been done it was just not my mum to see her like that. I said: 'Oh mum, come with me'. I got her dressed up a bit and did her hair nicely and put a bit of lippie on her.*  
[WG5, daughter]

The services that were utilised in the rehabilitation process during the hospitalisation experience began with personal cares, and moved on through the range of physical therapy cares one would expect to be available in a public hospital service. These were physiotherapy, occupational therapy, and speech language therapy. There was the briefest reference in the interviews to a social worker involvement, but none related to orthotics, or diversional therapy.

The education and the expectation of whanau to learn to care for their member affected by stroke varied considerably in the relating of their stories. This appears to be proportional to the involvement that the whanau had with the discipline and the nature of that involvement. There were accounts that demonstrated a paucity of information being given by the staff. An example of the failure of nursing to meet acceptable clinical best practice guidelines with a lack of the giving of a basic information briefing as to ethical issues involved in the care of their whanau member is given in this account:

*I did something wrong. They didn't tell me I wasn't allowed to tie him to the toilet seat and I did and you're not allowed to. And I got a good growling. I burst into tears. We used to put the red belt around him and clip it to the back because he used to fall forward. But they never told us we weren't allowed to. So I got a real growling.* [WG1, wife]

This relates to the issues surrounding the use of restraint. These issues are being carefully re-examined in our hospitals in Aotearoa/New Zealand today and in general terms now require informed consent to be given, verbally or in writing, by the patient or their next-of-kin. For this whanau the greater issue was the safety of their whanau member affected by stroke. Without being tied back onto the toilet chair there was a very real danger of the husband and father falling forward, off the chair, and onto the floor with all the inherent risks of personal injury that involved. 'Growling' at the wife is all she remembered of the incident, not of any discussion on safety and/or ethics. In this recollected memory it appears that the admonition to the wife was unnecessary. There could not have been any doubt that she was his next-of-kin, and that consent to

secure her husband from falling off the toilet chair was agreed to by her. Patient safety surely demanded the use of such restraint so that he could be left alone in private to complete his toilet functions?

Another wife relayed how variable and inconsistent was the instruction and ability to help her husband:

*Yeah, there were certain times when they would come and show me how, if they weren't (going to be) around, but they wouldn't let me do too much in that time he was in the hospital. [WG2, wife]*

This account seems to indicate that there was no planned formal instruction sessions in how to undertake personal cares and that the cares were only taught when the staff were not going to be able to undertake the cares themselves.

There were also accounts where it appears care was lacking by the staff. This is clearly illustrated in one account that demonstrated what appears to be an unsafe neglect of the patient.

*I went down to the shop while the nurses had him in the shower. I came back and he was sitting in there on his own, he was just hanging on, he was frightened. I had words, its not good enough. If you were busy you should have said. Someone should have stayed in there with him. [WG6, wife]*

The physical harm done to another whanau member may be able to be attributed to new staff to the area, or staff without a specific knowledge in rehabilitation techniques, however for whatever reason the shoulder dislocations occurred, it should be considered unacceptable for this to have continued on successive occasions:

*The only problem we had there was the nurses lifting his right shoulder, actually kept putting it out. I don't know how many times they did it until physio got really annoyed because it was too hard for him. So they had to put signs on him 'not to lift/stroke'. [WG3, wife]*

In contrast to the experiences of whanau whose member affected by stroke was hospitalised in New Zealand, the Australian experience for the whanau was one of not being able to share or learn to help with the personal cares and offers to do so were rebuffed by the hospital staff.

*You weren't allowed to do anything – I think they believe that if he did it and something went wrong then ....*

*Was there any training of you or other relatives?*

*No. No. The only thing I was allowed to do, I was allowed to rub his hands. We were sitting outside and he pulled himself up on the rail and that was a no, no. He got told off. Another time his brother helped put him to bed, got him to stand up. He got a growling; so you weren't allowed to do those things. [WG6, wife]*

There would appear to have been a fundamental philosophical difference as experienced by this whanau between the rehabilitation experience in Australia and that in Aotearoa/New Zealand. I believe that this difference relates to an operating difference between the concepts of dependence versus independence. Whanau were not invited to learn to share in the caring of their whanau member or was the whanau member actively challenged to try to do things for himself.

### **The independence of the patient**

Whanau members were a great encouragement to their member affected by stroke during the recovery hospitalisation experience as they encouraged independence and return to function. In many cases it appears that the determination that their whanau member was going to succeed in recovering function was instrumental in that recovery.

*It's all right, you are going to walk again you know, aren't you? You are. You are not going to give in, you're a (surname) remember? (surname)'s don't quit. Then he would try hard. [WG2, wife]*

The supreme faith and transference of determination from his wife that he would recover and walk again undoubtedly contributed to the ability of this man to walk out the door of his home with an orthosis on his affected foot using a quadripod.

The determination and resolute persistence of the husband as related in this account speaks volumes of his faith and his contribution to the recovery of his wife:

*Oh yeah, I mean, every day I worked on her and her hands would be, (put your hand down, speaking to wife), would be like that and I'd just tap that finger and tell her to move it and then she would just move it like that, and day after day, hour after hour, day after day, week after week, that was all I did until I got everything moving, and then her toes, and I'd whack them, yeah, move it, move it, you know, move it. And then I'd get her to squeeze my hand. She was asleep remember. Squeeze my hand, squeeze my hand, squeeze the bloody thing. So I could feel a little bit of*

*pressure, you know, and every day we would get just that little bit stronger and little bit stronger [sic]. [WG7, husband]*

The individual independence demonstrated by some of the whanau members affected by stroke would be an inspiration for others to persist and take a hand in their own recovery.

*At physio, those rails up the side you have to walk through; everybody had gone and I was in there all by myself. I liked that. So I looked around and said: 'Nobody's here, so I put this leg up on that side and this one there and here I am. I pulled this arm back to stretch and (was) walking back and forwards like this. Then this doctor came out and said: 'What are you doing?' I said: 'just doing a bit of stretching.' So I never gave up the thinking that I was going to get better again. [WG4, stroke patient]*

## **Preparing for discharge**

There does not seem to be any point in time or level of recovered function that indicated that the whanau member who had suffered the effects of stroke should be discharged. As the length of recovery time extended it became apparent to whanau that they were being readied for discharge. It is believed that none of the whanau really understood what the future held for them. One whanau referred to the reflections they had as they contemplated discharge:

*How can I handle this? What was it going to be like? Emotionally I wanted to talk with people who had the same, how did they cope, what was the first things they did? What did they prepare at home; how did it affect their whole life, and I had to think about all that. [WG3, wife]*

The quotation immediately above bears testimony to the perceived unmet need of whanau members. It would appear on the face of it that preparation of the whanau to ready them to take home their whanau member affected by the devastation of stroke was limited to essential hands on personal cares. The issues that the whanau member affected by stroke might face were not dealt with, either in informal discussion, or planned educational/preparational sessions prior to discharge. There appears to have been no discussion or consideration of the psycho-social needs and the difficulties that whanau might face coping at home. This wife recognised in retrospect that there was an intellectual stimulus deficit both for herself and her husband but she had no knowledge of what to do to rectify the situation.

*That's when I started thinking about, not so much the home help people coming in...just him and I. I mean I wasn't going anywhere so there was nothing fresh to talk about, nothing to bring in, nothing interesting, nothing to stimulate the mind for him. That's another thing that I thought it's just not happening, none of those things happened here.*  
[WG1, wife]

The comments of one daughter whose mother had been affected by stroke makes a poignant silent plea for serious consideration to be given to recognising that psycho-social problems can and will occur in the whanau of the member affected by stroke, and that comprehensive holistic care needs to be included in the ongoing treatment plan.

*When she started to become mobile and I kinda [sic] couldn't accept her as my mother because she had changed so much, her personality and everything.*

*It took me a long time to adapt to her, that this is my mother, you know, and it was quite horrible.*

*(Mother) And that made me feel quite sad.*

*Even my youngest brother too, he is still adjusting.*

*(Moderator) Was it because your mother had disabilities now that you found it hard?*

*Yeah. It was like she wasn't there for us, because she used to be there for us, for our kids, and just her whole self changed. Everything. She just wasn't like our mother. You know, another person.* [WG7, daughter]

An awareness of the impairments suffered by the whanau member affected by stroke and strategies as to how the whanau should cope with these was an education need that appeared to have been overlooked by the hospital staff as exemplified by this memory:

*It is quite hard at times but it's getting better. It's just hard because he can't talk. Like for me, I don't really know what he wants and that but I'm starting to understand what he wants now.* [WG3, daughter]

There also appears to have been a variable response to the perceived physical needs of the now disabled person and their whanau to be able to cope at home. In some cases it was blatantly stated they were expected to use the members of the whanau to help them. In other cases there was both an obvious lack of information about the availability of services and a neglect to provide services. The delegation of ongoing physiotherapy and occupational therapy programmes to the whanau is only acceptable if there was to be ongoing supervision of those

programmes. This does not appear to have occurred with any whanau with a member affected by stroke being readied for discharge.

The expectation that the whanau would get in and provide hands on care was exemplified by this memory:

*I guess nobody can really prepare for how difficult it really is. It sounded great. What they didn't tell me, yeah what's supposed to happen to his hand in the meantime?*

*'Well you know you need to bring family in.'*

*Well we can try but their intentions might be there but it never lasts.*

*'Well get the carer to do it.'*

*If it was that easy we wouldn't need physiotherapists because everybody could be trained in an hour to do all this physio. [WG6, wife]*

This whanau clearly expresses the ironical nature of the comments being made to them. Indeed they have every right to state that "if it was that easy we wouldn't need physiotherapists." What this wife goes on to describe is just how exhausting it is to continually provide ongoing personal cares in addition to the physical therapy cares. She opened her description with the comment that once her husband had been affected by stroke she began "the long haul." She went on to say to describe how tired she was and how her life had changed:

*That I think is the hardest part of all, where you don't get enough sleep because you have to get up during the night. You used to be up three times during the night for a mimi...it was two hours, two hours, two hours if I was lucky. After a year of getting up three times a night you do get tired.*

*(Moderator) It's 12 months on and I am wondering how life is for you?*

*Oh it's changed dramatically because I used to come and go as I pleased, he was always home for the kids. (husband) would vacuum, make the beds, do the washing...he'd cook the tea. But all that stopped, not that I minded. I do tend to feel housebound...its almost like being a solo parent having to do everything for the kids. Yeah that's what it feels like, a solo parent. [WG6, wife]*

The absence of community domiciliary therapy services in the rural areas of Taranaki was highlighted by the comments of this wife:

*So I really wanted (husband) in an environment where he could do something with other people, (where) he could see his achievements. So doing his exercises at home with me, really you can't see any improvement. And that's pretty boring, he doesn't want to exercise by*

*himself. It's like dieting alone, it's not fun. And so he didn't want to do things like that but he did a little bit. [WG3, wife]*

It would seem that the lack of follow up outpatient clinic rehabilitation is intended to be made up by work of the whanau at home however the lack of in home supervision by domiciliary allied health personnel is keenly noted as this wife related in summary with her remark that this was "like dieting alone." There is much to be said for the peer pressure of achievement to benchmark against as the stroke affected individuals would experience at a clinic with other similar patients so affected.

Reference has been made to the absence or inadequate consideration of the psycho-social needs of the patient and the whanau in preparation for discharge however the absence of information on services that would or could be provided following discharge was marked and not isolated to one whanau.

*They don't really prepare you for when you go home. They tell you some of the things that are available, but the real nitty gritty they don't. [WG6, wife]*

*So six months after he came out of hospital, I find out these things. They don't let you know you can actually have all these things. [WG3, wife]*

A very common experience that caused dissatisfaction and a feeling that they were poorly served was the limitation of the outpatient rehabilitation services to a maximum of six weeks post discharge. This termination of post discharge rehabilitation service quite often came unexpectedly. The limitation of these services for a six week period may well have been told to whanau before discharge but this is not known; the implications of it were certainly not understood if it had been.

*I waited for the van to pick him up on the allocated date. It didn't turn up. What's going on?*

*'Well that was only an assessment.'*

*So what you are saying is that you are not taking him back on the programme?*

*'Well no because he hasn't improved enough. You are not doing enough now, so you know you are wasting our time. You know we want to see the big results.'*

*That's the let down of our health system. [WG 6, wife]*

This whanau is entitled to feel aggrieved when they are made to feel responsible for the lack of progress of their loved one. The pattern of visits to the rehabilitation day ward based clinic for continuing therapy only occurred once or twice a week for a therapy time of 20 minutes for the maximum allotted period of six weeks. It has also been noted that in Taranaki it was the experience of these whanau that there was no domiciliary supervision of the in home ongoing physical therapy rehabilitation programmes.

A common experience that came through was the inability for home help/carer relief to be able to provide for the needs of Maori. One very strong message that came through from all the whanau was the importance for the whanau member affected by stroke to be at home but not confined to home. This confining to home not only affected the member affected by stroke but the lead carer as well and as much. Lead carers and whanau members affected by stroke referred to their inability to participate in the life of their Maori community and in their important cultural practices such as tangi. This needs to be acknowledged by empathetic service providers as a very important issue for Maori.

*The only thing that was a drawback to me though is going to tangis. I can't go up and you know, farewell that one and put him to rest. I'm not afraid of falling but I wouldn't want to do it. Do you follow? I don't want to upset somebody else. So I would rather stay at home. [WG4, stroke patient]*

This woman was of the belief that with her residual mobility disability that came from her stroke that she might fall and therefore cause a problem for others. She had a very firm belief that at a tangi the centre of interest was on the deceased and their whanau so she did not want to in any way to detract from that centre of interest which would have occurred if she fell.

Taranaki Maori have a proud and honourable history that they remember and revere. One of these moments in history relates to Parihaka. As a consequence many hui of significance for Taranaki Maori are held at Parihaka Marae. This wife wanted to attend some of these hui but waited almost two years before doing so, and then only when she was able to ensure her husband would be looked after:

*Then the hui at Parihaka and I'd say to him 'well I'm going to Parihaka today and I might not come back until tomorrow. You be alright?' 'Oh yeah I've got (son) over here and (son) down there'. And I sort of weaned that way, so he got used to it. [WG2, wife]*

The familiar environment of marae and Maori community centre has a real beneficial role to play for the whanau member affected by stroke as this quote testifies.

*We were both heavily involved in a club, we were members and he would be one of the cooks, and even though he hasn't been well we are still out there and are still members and he just has to sit there and the environment is healing as well. [WG6, wife]*

It becomes apparent from listening to whanau that their life does not revolve around the four walls of their home and that the wider community is equally as important. An unspoken but primary need for whanau is for them to have services and support service information that will enable them to participate in the wider Maori community again as they used to do before the stroke event.

These quotes from interviews are typical of the experiences of all the whanau interviewed which indicates that this is the experience of all whanau/families with post discharge service provision.

*I was really looking for them to say to me: 'here are some services to help you when you get home.'*

*The only service that was offered to us was the physio service in the (local) Health Centre, which only went for six weeks. Then that was it. The fact remains that there was nowhere to turn to really after that physiotherapy session had finished. [WG1, wife]*

*Then of course she went to speech therapy, that was ongoing, she'd go twice a week, the hospital van would pick her up but that (only) lasted for six weeks. I felt it could have been longer. I would have liked to have seen it a wee bit longer. [WG5, daughter]*

The lack of information about service availability to the whanau after discharge was at times unexplainable. Possibly the worst example recounted at interview related to one whanau whereby it was only during the focus group interview 18 months following the discharge from hospital was it revealed to the wife that she was entitled to have her husband referred to the Orthotics Department of the local hospital to obtain some specially made footwear. The wife was not aware such a service existed and that its facilities were available to her. She had been trying unsuccessfully around town to find some slippers that he could fit. This need was expressed during the interview in the presence of the Maori Disabilities Advocate who was able to write a referral immediately.

*They don't tell you what you can have, you know what services you can utilise. See, like I can't buy him slippers, I can't get them on his foot. I go round all the shops, nothing. My brother in law came here one day and had these boot slippers on and I said Oh where did you get those? Because they open right up. He says from the hospital. So I spoke to Ramona. [WG6, wife]*

This whanau also were unaware of the ability to have a referral for podiatry services (the wife expressed an unhappiness at cutting her insulin dependent diabetic husbands toe nails). This was also rectified by the intervention of the Maori Disabilities Advocate and referral to podiatry occurred.

*About cutting his toe nails...I am always scared I am going to cut the skin instead of the nail, so it's a hell of a thing. Now I find out that those services are available here. You know, if I want to use it. Yeah and this is what I am talking about, where they don't let you know. You can actually have these things. [WG6, wife]*

This whanau also needed a ramp that the Maori Disabilities Advocate was able to rectify when Occupational Therapy had deemed it "not necessary." This incident is recounted further on in this chapter.

For whanau where the key income earner was affected by stroke there were many issues around money and income to pay the bills and to live on. In one case the wife was not informed completely of the benefits she was entitled to. She had relied upon the Social Worker from the hospital to do this for her and it was not until six months post discharge that she found out there were other benefits that could have added to her income.

*Well actually you are entitled to an invalids benefit. And I said Oh. I thought all the benefits had been put into one, you know, disability, invalids, and I was quite surprised. You know that would have been about April or May. So six months after he come out of hospital, I find out these things. [WG6, wife]*

Another whanau who lived in a rural area related how they had one only visit from the Social Worker and then no more. They were not told she was not coming again, in person or by telephone yet the wife excused this cut off by saying that she (the Social Worker) had so many cases up there in New Plymouth.

*You know I couldn't ring her up every time I wanted something, or things weren't right because they have got so many cases up there, I've seen it*

*aye. That poor woman, But she did come out, and then she just stopped. Absolutely stopped. I haven't seen her. She was there in the hospital, to be quite honest though, she didn't do a lot for me. [WG1, wife]*

## **Home visits and home assessments**

A key function of a comprehensive rehabilitation service is to ensure that the residential environment is suitable for the discharge home. This is usually completed by an occupational therapist who makes a home visit, with or without the patient and their carer/s, and in the normal course of events occurs before the actual discharge. This enables the installation of handrails, access for wheelchairs to be assessed, and measurements made and orders given for bathroom alterations and the installation of ramps. These are just a few of the factors that a home visit will consider. The experiences of whanau interviewed for this study varied from no home visit to home visits with no follow up action occurring, or remedial action considerably delayed (almost four years in one case).

*They were going to send out a guy to put railings around here and there and in the toilet. That didn't happen until (husband) got his knee done. The Case Manager (for husband) must have pushed it through to Occupational Therapy and they put in some rails and made it easier for us to get in and out of the bath. She said: ' I don't think its (husband), I think it's you.' Because going down the steps I'm going backwards – don't worry it's the only time I'm backwards in coming forwards (laughter). She said: 'Oh look how long since your stroke?' I said not quite four years! [WG4, wife]*

This was the worst example of a delay in the provision of aids such as rails that would have made daily life safer for the whanau, however delays were an oft-repeated example of service provision deficit.

*It took about four months to get the shower altered so he could have a shower. Yes it was a long struggle. [WG 3, wife]*

There also appeared to be a gate keeping role played by some of the therapists whose task was to assess need and recommend that need be met. In many examples given by whanau there appeared to be some role confusion between needs assessment and service co-ordination. This has been demonstrated as a likely outcome in those NASC services where the twin roles of needs assessment and service co-ordination are performed by the same person. It would appear to

be a very difficult task to be able to accurately assess and recommend that all needs be met if that same person is aware of budgetary constraints for service provision. This has believed to have been the case in some NASC agencies and as a consequence many such agencies now split these functions between different staff members.

*Yeah. It's through Ramona that we got the ramp. What happened, OT did the session and says 'well I think, you know, he would do well with a rail' so they put a couple of hand rails in and I says well, why can't I have a ramp? He doesn't need it because he can walk. I says yeah, we'll see. So further down the track I says to her well look, when it's raining I can't get him outside because he'll get wet walking down the steps and if he's sick I have to take him out in the wheelchair because he can't walk. If he's not well his whole body seems to shut down, you know, starts to go all weak. I got caught a beauty one day. He was sick, the boys were home and they wheeled him out for me down the steps. When we come back from the Doctor nobody was here. I couldn't get him inside. So I rung up Ramona's and I said hey, have you got any males up there? Well, her son was up there, so he come [sic] straight down. I wouldn't have been able to get him inside. I would have had to go to the neighbours or something. You know, the other side of it, when it was raining the concrete gets slippery and becomes a hazard. Yes, so through Ramona, that's how I got the ramp. The OT wasn't being real about things. [WG6, wife]*

*It was the bathroom and the hospital was going as fast as they possibly could, but I was still disappointed in that. I actually asked for a walk in one and when they did the assessment they said he didn't need it. I still think he needs a walk in one. We never got it. [WG1, wife]*

In all cases the whanau then just "got on" but could not help observing others who were disabled.

*We started learning him, teaching him, and then when the time came for him to start washing himself, to sit on the seat you put across the bath, but I still think it would have helped me a bit more with a walk in one. It wasn't trying to keep up with the Jones's. I mean I have seen other people with them and I don't think they were as bad as him and they got them and I've got to say this – they weren't Maori. [WG1, wife]*

## **Conclusion**

The events related here, are unique to the individual whanau that relayed them to me. The circumstances surrounding the experiences, particularly those following discharge are probably not much different from those of non-Maori experiencing a devastating sudden onset incident such as stroke but are unique because they are whanau experiences. However what does come through in all the interviews is how the partner seemed to be able to draw on an inner strength for the perceived benefit of her partner. In addition the powerful influence and impact of the whanau is reinforced time after time. From these descriptions of the whanau experience of stroke that have been related we now move to look at specific Maori perspectives of the stroke event.

## CHAPTER SEVEN

### A MAORI PERSPECTIVE

#### Introduction

In this Chapter I have attempted to bring together those things that are specific to Maori and to interpret those experiences from the Maori perspective. I have been guided by the members of my research whanau to ensure that the Maori worldview is the one that is expressed and not that derived from my own experiences. A number of themes evolved out of the reading of the data and these were:

- a) The importance of whanau
- b) services and service availability, specifically Maori based services
- c) those things particular to Maori and their import
- d) the need to be at home but not confined to home.
- e) the integration of traditional and non-traditional methods of caring

Specifically in this chapter we shall examine and relate:

- a) the importance of the whanau
  - i) in recovery
  - ii) tamariki and mokopuna
  - iii) manaakitia
  - iv) in getting on with life
- b) those things particular to Maori and their importance
  - i) taha Maori
  - ii) karakia
  - iii) mirimiri
  - iv) Te Reo
  - v) knowledge from their tipuna and wai
  - vi) age and gender considerations

These themes contain much that can be distilled to reveal a truth that relates specifically to Maori.

#### The importance of whanau

When non-Maori are privileged to experience the telling of stories as I have been enabled to do then they can begin to understand the absolute, all pervasive

outreach as manifested in the expressions of caring, nurture, support and protection of the whanau. It is difficult for non-Maori to appreciate the great support and comfort that is experienced by the individual whanau members from the collective of the whanau. The place of tamariki and mokopuna within the context of the whanau takes on a whole new meaning and importance as one listens to the stories of the whanau focus groups I was privileged to listen to.

Tamariki and mokopuna are an integral part of the whanau. In a number of cases examples were given of the support that the lead carer received from tamariki and/or mokopuna following the initial admission to hospital. These examples varied from the presence of a mokopuna staying in the room with his grandfather to support his grandmother, through to a son taking over responsibilities for the personal cares his father needed assistance with. Examples to illustrate these aspects of support and nurture that were forthcoming from within the whanau are given in the previous chapter.

It became apparent as the study progressed that tamariki and mokopuna were regarded as important as the whanau member affected by stroke within the household and in fact the home was not home without them. Upon discharge home whanau home life had to be restored to what it was previously. This was seen as essential for the health and wellbeing of the whanau, not just for the member affected by stroke.

*I brought them all home the day I got home; asked them to bring all the kids home. I had them all home. [WG6, wife]*

*The family was the key thing and I still maintain it is the key thing. Bringing (husband) home to his home environment with no grandchildren was just stupid because that's not the home environment. [WG3, wife]*

One lead carer discussed the problems of children and mokopuna not understanding the situation with their father and grandfather.

*L's sister spent quite a bit of time sitting the kids down and going through it with them...this is how your grandfather is and you kids need to do or not do. It just went over the top of them because they don't really understand...they don't understand that any stress in the house that he is affected by it. [WG6, wife]*

The thought of these children going to stay with other whanau members was not even a consideration for this mother and grandmother. Her comments only reinforced the comments of another wife: without the tamariki and mokopuna

"that's not the home environment" even when this causes problems as sometimes children do just by being children.

In stating that the hospital experience of whanau with a member affected by stroke is probably no different to that of non-Maori in similar circumstances could be seen as denigrating one of the essential functions of whanau that is not present in many non-Maori family groups but this is not the intention. I am referring to manaakitia, the capacity to care, which is stated by Durie (2001) to be a critical role for whanau. Durie states that: "unless a whanau can care for the young and the old, for those who are sick or disabled...then a fundamental purpose of the whanau has been lost" (p. 200). Whilst there are non-Maori families that have the capacity to care deeply for their loved ones it is the unique feature of manaakitia that makes the whanau experience so different and special.

The concept of manaakitia is no more clearly demonstrated than in the actions of the partner/spouse and other whanau members during the hospitalisation experience and on into the early days of discharge home. These demonstrations of love and caring were spontaneous and appeared to occur without any fore thought. They were expressions of manaakitia.

*My brother says: 'right we're going to Aussie; I'll book your ticket and I'll go with you.'* [WG6, wife]

The spontaneous actions that occurred without thought of personal feelings or needs were conveyed by many of those interviewed. For them this commitment was instinctive; it just occurred without any conscious thought, it was not something to think about.

*And when he fell asleep he fell asleep, but as soon as he woke up he would reach out his hand and I made sure I was there.* [WG2, wife]

Talking to whanau it quickly became apparent that they did not see they were doing anything special in their caring. It was just something they did for their whanau member. The whanau as a collective demonstrated great strengths, however some individual members of the whanau stood apart and demonstrated skills and strengths that were notably special. The concept of manaakitia is unique to the actions of whanau members, and provides an explanation for their actions.

*It all became so natural after a while. You are not really doing anything special any more, its what you do. Like getting up and cooking your kai,*

*its something you do, its not an effort, its not a special activity out of the ordinary.* [WG7, husband]

This husband and his whanau undertook cares that few families would contemplate. Initially the wife was brought home, unconscious, to die and when she showed signs of recovery was readmitted to hospital to make that recovery. Upon going home after recovery of consciousness and sufficient physical function to enable her to do so, the husband and his whanau set about continuing to care. The specialness of that care as seen by an outsider was put aside and stated to be 'not a special activity out of the ordinary' by the husband, who I emphasise was speaking for his daughters as well.

This expression of caring mirrors that of the wife who stayed in hospital with her husband the entire seven weeks that he was an inpatient. While he was a patient she had felt it was her place to be by his side but did not consider this to be anything special.

At another interview a kaumatua who was part of the whanau spoke about his concerns as to the burden of care being carried by the daughter in caring for her mother:

*Everything about the situation, how she had to cope with it, I could see it was hard for her. I wasn't so worried about me knowing we were all related. This is what Maori are like. I'm not saying about Pakeha they don't do that, but we have it bought up with us in our hearts to care and go on through the process what (we) learnt.* [WG5, kaumatua]

His final statement reflects that concept of the totality of caring of the whanau.

Whanau members readily acknowledged the special contributions made by other individuals from within the whanau, as instanced by this comment of one sister observing another sister:

*My sister, gosh. She helped nurse mum. I couldn't do it, I just couldn't do it, but (sister), she was that good. I've never seen that side of my sister before.* [WG7, daughter]

The actions of caring of some whanau members gave illustration to the concepts of interdependence rather than independence, which for Maori is a quality that shows great personal strength of the individual. In this case the son gave up his future career to come home and care for his father.

*Well my son was getting his Teachers Diploma and he had one year to go and he came home, they all came home, and they sort of got together*

*and said someone's got to help mum and because he's got no children and other things to worry about. He said 'I will.' (Son) came to live with us. Now he did the showering. He did the shopping for dad's kai. He started him walking up the street. We were actually offered a wheelchair but he said 'no,' he's going to use the walking stick because he was dragging his foot. But (son) meet all his needs, met all his needs. [WG1, wife]*

This son stayed in the home of his parents for 15 months undertaking all personal cares assistance that was required. In addition, he undertook the physical therapy rehabilitation exercises and retraining that his father required in the absence of domiciliary services being provided in the home.

The collective numbers of the whanau were very important. From their collective presence great personal comfort and strength was derived, particularly by the partner of the whanau member affected by stroke. This was very pronounced in the acute initial diagnosis phase in hospital and on after discharge home. It was also noted that it was something that just seemed to happen without a spoken word/request.

*I had my sister here and my mother here and a couple of cousins and support people and they were doing everything for me. [WG3, wife]*

*And being with the whanau. That was the most...the closeness. [WG3, wife]*

The understanding of the importance of self esteem of the whanau member affected by stroke and the nurturing of this as fostered by the whanau members was no more clearly expressed than in the case of the man who had been working his farm right up to the stroke event.

*I suddenly realised, we were talking over their dad. When they were gone he actually blew up – bring me back to reality that [sic]. 'Hey I still have a mind too, you know, I still have an input into the farm.' I said to (son) 'when you come to discuss farm business please talk to dad...don't talk to me about it and not include your dad. [WG2, wife]*

This lady went on to discuss the importance for her sons to continue to involve their father in discussion as to the management of the farm. Initial concerns by the son that this might 'worry' the father were put aside as the wife recognised that her husband needed to continue to feel worthwhile with a contribution to make: "it's important that he has that input." By enabling this continued

participation and sharing in the functioning of the whanau, self respect and respect, one for another, was maintained.

Another wife, with her caring, nurturing and perception, clearly articulated the need of the member affected by stroke to be considered as still having a contribution to make to the functioning of the whanau with the very astute observation:

*The important thing I found is not to take that independence or whatever that he developed, because it's cruel to see a grown man being the foundation of the family and your taking over everything in the house...you've got to include him, and just keep going...and he's still the head of the house when it comes to the chequebook (much laughter).*

[WG3, wife]

## **Things particular to Maori**

The importance of the holistic Maori world view of life and health is very positively emphasised in the accounts of the interviewees that dealt with how important was taha Maori and those practices of karakia, mirimiri, and the knowledge of the ancients<sup>4</sup> to them and their fellow whanau members. The accounts are all important in their own way, carry their own message, and have a significance that is peculiar and special to that whanau. I have indeed been really privileged to be allowed to share these experiences.

The husband of one of the whanau members affected by stroke gave an account of returning to the ways of the ancients, to the very roots of his Maoriness. The story he related had much silent testimony as to the powerful attachment that Maori have to the whenua. Whilst in his everyday life he had turned his back on the ways of his tipuna, in the moment of deepest crisis in his whanau, it was to the tipuna that he returned. The taha Maori that "kicked" in for him, the appropriate tikanga of purification with water and the karakia he undertook in the forest in the early mornings led to his communion with the Gods and his searching questions of Atua. This man and his whanau were faced with the situation of having an unconscious wife and mother they had brought home to die on the approval of the hospital authorities. She was not expected to live more than another four to five days. The unknown and desperate future they confronted had a powerful impact on this man and his whanau. His experiences

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<sup>4</sup> The term "ancients" is used as this was the word used by my matua key informant in relating his experiences. Likewise I use tipuna instead of tupuna as this was the spelling preferred by the members of my Taranaki Maori research whanau support persons.

are relayed for the reader to judge for themselves the powerful influences that are alluded to by many but actually experienced by few:

*Oh yeah, it tipped us over all right. Our whole lives completely upside down.*

*Everything you ever believed in and everything you ever did in yourself, it just didn't matter any more. I'm a person who builds things and makes things happen, I can do things, you know, I'm a very practical person. I've built houses, I've shorn sheep, I've cut scrub, I've fallen bush, I've worked in the Freezing Works, all that sort of stuff, but this is just off the planet completely.*

*'You are never prepared for something like that are you?'*

*No, and I don't think you can be, you know. Gosh, I mean you ask the questions 'what the hell have I done, what have we done'. It was about just changing the whole pattern of thought.*

*Well I guess our Taha Maori kicked in, in a big way, you know, because there was bugger all left for us to attend to, you know, we turned to our Taha Maori, it's something that I have always put 'over there' and done my thing 'here' and all of a sudden you start reaching back into your own self.*

*It was amazing really, the way the karakia that went on. You know we had faith healers from Maungariki, we had faith healers from Wanganui, we had our own priest and you know parsons who were friends of ours, who came and that sort of thing. I did get tipped over when our own Catholic Priest delivered what we call the Karakia Tuku Tuku, that is the last rites. I didn't handle that, you know, dust to dust, ashes to ashes. It was then that I really went back inside myself.*

*And it's not something I would want to do again either. But it was all we had. You know, we had nothing else. Well, you know, I was brought up with an old... my adopted father was an elderly person, and he was very steeped in his tikanga and his way of life, he belonged to that old world. It was not something I accepted, right? I wanted to move in the flash new world, get a job, get a flash car, be a millionaire by 30. All that stuff. It never happened aye. So when this Father delivered the last rites it was at that point that I knew I have to give it a go now. I'm not saying that I was successful, but I went back into the bush early in the morning before daylight and I stripped down, washed myself and started to karakia. You know, my karakia wasn't a plea at all. I mean, I was*

*demanding from Atua, what the hell are you doing, you know, I was up there, flying around the bloody stars, you know, it was a complete turn around to who I am or what I am, even now, I just don't want to go back there, I don't want to. And then I came back down and early in the morning I washed her. And from that point on I never stopped the karakia. Never stopped it. I can't explain those things. I can't explain it.*

[WG7, husband]

Karakia is an often misunderstood and unseen part of the life of Maori yet its importance cannot be underestimated. Karakia accompanies every activity of daily living and is an integral part of all tikanga. The importance of karakia comes to the fore in time of sickness and need, both for the affected whanau member and the whanau as a whole. The husband's account printed above carries on with these comments specifically related to karakia:

*Well, there was only one thing left and that's your karakia. I saw a notice the other day that I think epitomizes what it was all about and it said: 'Don't make your karakia the last resort, make it the first resource'. And I thought, yeah, that's right, we wait until something damn well happens to us and then (laughter). I have probably not quite a Christian view of karakia. I think I guess if I was to say something it is a dollar each way, you know, mixing Christian with the things I knew from my past, from the way I was brought up, but to be karakia, whether it's any karakia, it's good, you know, so yep, I guess my biggest advice is 'don't forget your karakia' It doesn't matter what language, even God can hear the mute.*

[WG7, husband]

A regular karakia session was held at his wife's bedside every evening at 7pm. After a period at home a sister asked where a broom was and the whanau were astounded to hear the wife (still unconscious and expected to die) state that it was "in the bloody wash house where it always was." Karakia was attributed in part to this recovery:

*Every night at 7oclock we had karakia.* [WG7, daughter]

*You have got to have that taha. I think it's a holistic thing, not just one person's effort, the karakia is part of it, her own taha is part of it, the kids love her and that's another part of it; its all those things together.*

[WG7, husband]

Karakia played a very important role on all the stories and experiences of stroke that were relayed during the focus group interviews.

(Moderator) *Your memories about the time in hospital – remember much about that? Not in the first few days. A lot of people used to come in and said (sic) prayers. [WG2, stroke patient]*

*Then I'd karakia, then I'd forget where I am and another prayer will do...that never leaves you because you are everlasting praying for them all the time, not so much for yourself. [WG4, stroke patient]*

*I went straight to my Mauri – my spiritual. Well what I mean about going to my spiritual, there was no one out there to support me in the flesh, but I have been taught over the years the first thing you do (is karakia) for support to help you get through anything like that. [WG1, wife]*

Karakia requires a belief, a faith in the intangible. Non-Maori would refer to the unseen power of prayer yet for Maori this is too simplistic to be regarded as an explanation. For Maori the influence of the Gods, and there are many of them, are traced back to the beginnings of time where Io (or Tua-Atea) the supreme God is the transcendent eternal world of the spirit that is the ultimate reality. (Marsden & Henare, 1992). The ancient ones (tawhito) are considered to be the spiritual sons and daughters of Ranginui and Papatuanuku (heaven and earth). These include Tane (of forests), Tangaroa (of the sea), and Rongo (of herbs and crops), to name but a few. The Earth Mother, Papatuanuku, who birthed these gods is considered to be a living organism who provides a network for all her children to live and function in a symbiotic relationship. The use of karakia is the method that Maori use to link back into this huge spiritual support and their eternal relationship with Papatuanuku. It is a relationship that is nurturing and sustaining, ever present and enduring, for the individual and the whanau.

A tangible expression of faith and belief that has been handed down from the tawhito is seen in the practice of the use of rongoa and mirimiri. Mirimiri is often dismissed as "just massage" but has a honourable and proven tradition among Maori. The partner of one whanau member affected by stroke demonstrated this and was fortunate that she encountered an enlightened doctor, prepared to let her continue what she was doing.

*I remember our kuia Turu; remember Turu? (talking to her husband). I remember. I used to listen to the old people, yeah we both did, and I'd hear them talk. How they used to get the oil and heat it...massage behind the ears. Continual massage with this oil right down to the back of the neck, and that's what I was doing all that time.*

*I remember them saying (the old people) that that will stop it, the whole facial disfigurement, but it has got to be continuous for 24 hours and that's what I did while I was there. I told the doctor about (the massage) while they were examining him, because he was asking me: 'What am I doing?' I told him about the old cure and he said to the nurses: 'Move aside, let her.' You know (to) leave a bit of room for me to keep it going because you know we could learn from this. Well this is what they used to do, because I know, I've heard them and I've seen them do it. She (Turu) said it's important that you deal with I straight away; you know you get any natural oil, warm it, it has got to be warm, and you massage gentle but gradual pressure on the points, and she showed me how to do it. [WG2, wife]*

To see the husband today with no facial disfigurement or speech impairment, is to marvel and wonder at the efficacy of mirimiri applied continuously with unrelenting devotion by his wife.

This expression of taha Maori, the practice of mirimiri, is but one of the many practices that are properly considered to be taonga to Maori. A very highly rated taonga by Maori is Te Reo. Te Reo is the language of the Maori; some would say it is the culture of the Maori. It is through Te Reo that the customs, beliefs, values, hopes, history, prayers and dreams of the people are passed on. Te Reo is one indicator that gives Maori their unique identity. It is acknowledged that many Maori do not speak Te Reo however it also needs acknowledging that Maori from all age groups are enrolling in increasing numbers to learn the language. For Maori, Te Reo is sacred because it was given to them by the Gods. Maori believe that Te Reo has its own mauri, its own life force, that gives it power and vitality. The subtleties of the words and the nuances of expression contained in the Maori language have untold meaning and value to the speakers of Te Reo. The importance of Te Reo to Maori, and in the setting of this study, was graphically illustrated to me when I was accompanied by a distinguished kaumatua to the home of a potential whanau group to see if they would participate in the study.

*I noticed the first time I met (stroke patient) that Matua spoke to him in Te Reo and he really responded. This has obviously been a very important component in his recovery? [WG1, Moderator]*

*Oh most definitely. And I am glad that we have that kohanga because that was one way of actually communicating. (WG1, wife)*

The kaumatua had previous involvement with this man prior to having his stroke but had not seen him for some time. The wife informed me that her husband often sat with an expressionless face when visitors came to their home and showed no interest in the conversation going on around him. On this day it was apparent that he gained a great personal boost to his self esteem and involvement with the happenings in his own home as the kaumatua talked to him at some length about life and shared experiences from the past – all in Te Reo. As a silent observer I noted that the husband's relatively flat expression gave way to an animated appearance and he shared in the conversation as an equal with the kaumatua.

The significance of the importance of Te Reo is further highlighted in this example from the same whanau:

*I wouldn't say speech therapy because that didn't really happen in there in English, because he (husband) wouldn't conform. It was my son translated their mahi into Maori and then dad responded. [WG1, wife]*

This use of Te Reo in mainstream rehabilitation service provision was of significance to this whanau and the progress of recovery of their whanau member affected by stroke. The importance and significance of Te Reo is further highlighted in this quote:

*Oh most definitely. And I'm glad that we have that kohanga because that was one way of actually communicating. Now when I feel myself getting a bit uptight with him and I can't get through I just go back to te reo and its not as domineering. I don't feel it's domineering. [WG1, wife]*

Would an English speaking person acknowledge that their language was domineering? The subtitles of Te Reo for this Maori woman quite obviously soften the emotions but still allow the passions to be expressed.

The influence of the knowledge gained from their ancestors, their tipuna, covers many aspects of life and this is no better illustrated than with the obtaining and use of water (wai) from a source revealed to the whanau from their tipuna. This whanau lived many kilometres north of New Plymouth in a remote country area. On their land was a small spring and from time to time they took wai from it because of its clarity, its purity and its pleasant taste. This whanau now have a small business bottling and taking wai into New Plymouth to a group of regular customers. The presence of this spring is quietly credited to the tipuna but although not stated to possess healing properties it was considered very

important to the whanau member affected by stroke. The husband used to bring this water into the hospital for his wife.

*While I was in hospital I loved getting the water.*

*If it shuts off tomorrow it won't affect us.*

*It might affect me.*

*It's something our tipuna gave us. It was really pure. It was very good for (wife).*

*Well it certainly helped her and she had to as part of her rehabilitation, she had to drink a lot of water. [WG7, husband and wife]*

Taha Maori and all the many and varied parts that comprise this, in particular karakia, mirimiri, and the teachings and influences of their tipuna, as discussed in this chapter had a significant effect on the experience of whanau affected by stroke. In all cases the reaching into their taha Maori enabled the whanau to cope with the difficulties of the changes the stroke made and is making to their lives.

## **Respect for age and gender**

It is recognised as part of correct tikanga that there needs to be gender specific care and sensitivity shown towards Maori woman (Bevan-Brown, 1998). In a hospital setting this means they should have age appropriate and gender appropriate assistance with personal cares. Whilst the following quote could be said to be indicative of a spirit of independence in the whanau member affected by stroke it was actually based in the woman's own feelings of inappropriateness for young males wanting to assist her in her shower.

*They couldn't understand why I was able to do things rather than have them done for me. Even getting in the shower and things like that. I sent the orderlies out, the male nurses. I'd say: You can run off now, I can manage all this. He said: 'No I'll wash your back for you and do your hair for you.' Run away, young boy; I'll push the bell when I am going to drown. [WG4, stroke patient]*

This account demonstrates a sensitivity that many women would face when confronted by male bathing orderlies – a practice common in many of our public hospitals. In this particular case the physical impairments of the patient were such that she was able to do much of her own cares although she admitted she could not do her own back. The use of male orderly bathing and lifting teams as is common in some of our hospitals needs to be examined for the insensitivity that occurs because of the female patient/male orderly interaction. The female

patient has the right not to be placed in the situation that this patient was in having to assert her will in requesting that she be left alone in the shower with all the inherent risks that entailed. These concerns are even more pronounced with the older Maori woman.

### **The patience and tolerance of Maori**

An aspect in all the interviews that became apparent, an aspect that is I believe a particular feature of the Maori psyche was their desire not to be seen to be passing judgement on the health services with which they had had their encounters. Maori have demonstrated many times in Aotearoa/New Zealand since the signing of Te Tiriti o Waitangi a patience and tolerance as they have sought all peaceful but persistent means to rectify wrongs done to them with abuses of the Articles of the Treaty. There have been numerous court appearances, petitions to the Crown, and personal submissions to local and national Government, yet iwi, hapu and whanau have never given up. They have persisted. One could suggest that they were motivated by the truism that "right will out."

This same patience and tolerance was demonstrated several times during the retelling of their experiences when whanau refused to blame individuals and institutions for deficits in care they personally experienced.

*I have a very firm belief that the hospital were to blame, are to blame, and I will die with that...I'm not belittling or speaking bad of the hospital because the hospital were very good to us. [WG7, husband]*

It is difficult to reconcile the conflict embodied in this statement. It is believed that the hospital were to blame for what happened to the whanau member, yet they stressed that they were not speaking "bad" of the hospital in saying so.

When it came to service provision and the many deficits that were highlighted in the telling of the whanau experiences, many whanau freely acknowledged that there was a scarcity of resources, and in particular, Maori service providers and Maori health workers. These whanau were very quick to ensure that I understood that they were not apportioning blame, or to seem ungrateful for the services that were made available to them. The services might be deficient, and they could see that, but they were not condemning them.

*Hey listen I really don't want to be putting our Health Workers down, Pakeha or Maori, because there isn't enough people out there to do this*

*work. I can understand that. That is the frustration, there's nothing out there, there's nothing.* [WG1, wife]

## **Conclusion**

Maori have specific values, beliefs and practices that they trace back to the beginnings of time as they recount their whakapapa. Whilst many whanau members in this study had differing levels of knowledge of these beliefs attributable to the tipuna, they all had an unswerving belief in the efficacy and value of these practices even if they may not have fully understood the basis of them. In this chapter I have recounted the specific taha Maori beliefs and practices that were recounted during the interviews I recorded. I now move onto a discussion of the significance of the analysis of the interviews and data that was collected during the study.

## CHAPTER EIGHT

### DISCUSSION

#### **The Whanau experience of stroke**

The principle thrust of this study was to develop an understanding of the experience of whanau in caring for a member disabled by the effects of stroke. The seven Focus Group interviews that I was privileged to conduct conveyed the experience of stroke through the eyes of these whanau as they had lived through it and were continuing to live the experience. It is worthy of note that all the whanau groupings wanted their story told for the potential benefit of others but yet all were self-effacing in saying that they did not think their story was anything special.

During the story telling there were moments of poignancy, moments of pure magic, moments of deep wairua experience, moments of tragedy, and moments of uninhibited joy accompanied by much laughter. Above all I was left with the powerful impression that for Maori there is something unique in the way they encounter, then deal with the effects of a sudden and catastrophic incident that affects a whanau member. In this study such an event was the occurrence of stroke. The Maori worldview played a significant role in how whanau members reacted to the situation.

One thing that came up quite clearly in reviewing the data and analysing the interviews is that the expectations of the whanau with a member suffering a stroke are no different than any other family who also suffered a stroke. They want and need access to services to assist them to care. They want and need information about those services to assist them to care. Whanau will readily respond to the requirement to care but need teaching, and ongoing education and supervision to enable them to care more comprehensively. If this teaching, and ongoing education and supervision were provided it is believed that there would be a lessening of the burden of care currently being placed on the whanau.

In all but three of the whanau, the control of money and household management was the responsibility of the female partner of the whanau member affected by stroke. The exceptions were the whanau where a widowed mother lived with her daughter and son-in-law, and the two whanau where it was the female partner that had the stroke. This pattern follows the evidence presented by Taiapa

(1994), and Fleming (1997) that Maori women are the ones responsible for the management of food and money at hui and this expectation follows on into the management of the household. It was noted that for Maori, money was not seen as a power or status symbol, but a necessary resource to be managed. In the context of this study it was apparent that the lead female carer carried a large burden of care of her husband, her mokopuna and in some cases her tamariki, with only a benefit income to fund the operation of the household and all other commitments. As the caring for the whanau member affected by stroke was considered a natural thing to do' the fact that it was unpaid work was not even considered. It was however noted that when the stroke occurred the socio-economic status of the whanau decreased markedly, adding further to the burden of caring and stress levels experienced by the lead carer. The meeting of the needs of the individual whanau member was the tangible expression of manaakitia as expressed in the actions of the whanau lead carer (be it stroke member, mokopuna, or tamariki).

Whanau will unwittingly and instinctively demonstrate a lived commitment to the many dimensions associated with the various Maori concepts of health and wellness. The inter relatedness and integration of these many dimensions requires hospital and rehabilitation services to adopt an attitude and an environment that facilitates the expression of care, nurture and aroha of the whanau in its totality. These services should aim to facilitate, support and accept these comprehensive expressions of care in action.

### **Support for the whanau to care**

An issue that needs to be examined is the attitude where the unreserved expression of care in action by the whanau is taken for granted by hospital and rehabilitation services. It is a matter of great concern that it is acknowledged by the MOH (1998) that in regards to disability, whanau support is expected to be provided without any cost. The same expectations are not stated as being expected of non-Maori families. This is not only unfair and unreasonable, it places an extra burden on the whanau and lead carer of the whanau member affected by stroke.

There were many examples given throughout this study where hospital services accepted and supported care provision for the whanau member affected by stroke to be able to be given by the members of the whanau. However it is apparent that the ability of the whanau to care for their loved one in totality

discharge in the home environment is deficient. It is evident in this study that services must be designed or adapted to enable Maori caring for former patients at home to continue to participate in the wider Maori community life. This requirement for participation in the Maori community life applies both to the whanau member affected by stroke and their whanau members. The adaption of services to enable this to occur does not have to necessarily mean more expensive service merely because the service will be delivered in a different way.

In relationship to the cultural life and needs of whanau and whanau members, there is a huge need to be able to participate in the life of the marae and in their iwi, hapu, and whanau cultural practices. Attending tangi, including the overnight stay that this may entail, is an integral part of these practices that should be able to be considered by the provision of adequate, flexible and comprehensive carer support. It is a commentary worth reflecting upon that a wife has to wait almost two years before her partner affected by stroke is sufficiently recovered in physical function that she can consider leaving him to attend such an event, with a son giving observational care of the husband and father. Under present operating procedures carer relief can only be provided in the home during the day. It appears presently impossible for carer relief to be able to "sleep over" so that a partner could leave her/his stroke affected partner and go to a tangi or to important hui. The flexibility needed to enable this to occur need not cost any more than the rigidly inflexible services available now but would contribute so much to the life satisfaction and fulfilment of our whanau member affected by stroke, his/her lead carer, and the whanau as a whole. As previously stated the whanau is expected to provide these caring functions without cost. These inflexible attitudes are based on the presumption that there is a large whanau 'out there' and they will provide. This could be considered as a modern day expression of colonialism that at its worse denied Maori a full social welfare benefit because of the stated belief they could feed themselves from their own lands (Murphy, 1997).

Although the whanau is able to place their loved one into residential care for up to 28 days per year utilising carer relief provisions available through financing provided by the Ministry of Health, this is an option rarely accessed by Maori. This option for carer relief, including that for long term permanent residential care, goes right over Maori whanau values and beliefs. For most Maori I have talked with there was no question as to the belief and attitude that it was the whanau that would do the caring. Where it is not possible for an older Maori man or woman, to remain in their own home the individual will be brought into the home of one of the whanau. Where the whanau may be widely scattered

throughout Aotearoa/New Zealand and direct supervision or nurture of the older whanau member not possible, often now we will see the move to a kaumatua flat. These are groupings of small flats, on or close to a marae, where the individual is able to live an interdependent life in a supportive environment.

## **Transport issues**

After acknowledging the essential ruralness of greater Taranaki and the sparseness of its population, the lack of ready transport for disabled persons needs to be considered. One whanau interviewed lived in Stratford, 42 kilometres from the main hospital and rehabilitation service where the main outpatient day clinic services were provided. There was a small limited functioning outpatient rehabilitation clinic service offering primarily physiotherapy available in their country town and a small service further south at Hawera hospital that they were able to access. However unless one has their own motor vehicle that access is denied them. This raises not only the issue of transport but also the issue of the lack of domiciliary rehabilitation physical service and supervision in the whanau member's own home.

The Mobility Voucher scheme that gives a 50% reduction in the price of taxi fares for the disabled person that operates well in New Plymouth and other urban areas throughout Aotearoa/New Zealand is not a ready option for persons living in rural centres needing to travel the sorts of distances they are faced with. If they do not have their own reliable motor vehicle and/or a ready supply of willing friends and neighbours to drive them, then not only additional service provision is denied to them but also participation in the life of their community and marae. A daily bus service provided by the DHB to run between New Plymouth and Hawera does not provide a suitable option for many. The times it runs are not compatible with clinic appointment times, and for the disabled individual access onto and off such a vehicle is difficult, if not impossible for some.

The sheer change in one man's life by the provision of a mobility scooter needs to have been seen to be appreciated. Living one and a half kilometres from the main shopping centre and the supermarket in particular; markedly disabled by his stroke but able to walk around his house; any trip to the shops was out of the question. For two years this man sat in his chair in the lounge or on the veranda, unable to leave his property independently. The provision of a mobility scooter brought a new sense of self worth to this man in that he was now able to

take himself up town, buy a few groceries, and be part of his local community again. It was the intervention of the Maori Disabilities Advocate that enabled the scooter to be provided. The availability of this type of mobility aid was an example of service provision information deficit experienced by a whanau. They had never been informed such assistance might be made available.

These transport issues not only affect the ability of the whanau member affected by stroke to access ongoing rehabilitation physical therapy, but also to continue to participate in their community. The issues surrounding the use of their own reliable motor vehicle, and/or the use of friends and neighbours to drive them to the marae, for example, takes on a whole new dimension when faced with the residual effects of disability caused by stroke. An example of this would be the access in and out of a car made difficult by residual hemiplegia. Whilst these issues are simply dealt with in larger urban areas with wheelchair and specialty disability vehicles, these options do not exist in rural areas.

It cannot be emphasised enough whilst it is important for the whanau member affected by stroke to be in their own home, they must be able to continue to contribute and participate in their community. For some this specifically meant participation in marae activities. This imperative also applied to their lead carer and as previously stated for one wife her inability to go to Parihaka for two years was a huge cultural loss for her. Above all else it was the provision of reliable, regular, reasonably priced public transport system that would enable older persons to be active in their communities, especially in rural areas (MOH, 1997).

### **The importance of whanau**

Taha whanau clearly expresses the importance of the family as the primary support system for Maori. It is the whanau that provides the physical, emotional, and cultural care to the individual members of the whanau. The care given by whanau as expressed in manaakitia supports the regaining of function and independence of the person affected by stroke but also provides much of the explanation of total caring so willingly given by members of the whanau, as it is needed.

The "sense of purpose" described by Durie (1994) as a function of the whanau (p. 73) is demonstrated as the whanau begins its care in the initial post diagnosis period. The whanau as a collective demonstrated great strengths, however some of the individual members of the whanau stood apart and demonstrated skills, strengths and manaakitia that was notably special.

I found the devotion to their partner expressed by the actions of the lead carer to be inspirational. This caring was demonstrated by the wife who stayed with her husband the entire seven weeks he was in hospital; the wife who would not leave her husband's side in those first days following the stroke so that when he woke she would be there as he reached out to hold his hand; and the husband who dismissed his love and devotion as 'not doing anything special any more, it's what you do.'

An aspect of whanau life that is difficult for non-Maori to understand, figured very prominently with one whanau. I refer to the dichotomy between interdependence and independence. I have great admiration for the son, one year off from obtaining his teacher's registration, who gave it all away and came home to care for his father. For whanau a sense of purpose in their individual lives is given by such actions. This young man was expressing a level of maturity and strength that was recognised by his whanau as he put aside his career for the needs of his father. Yet he would not have said he was giving up anything. He was meeting the needs of his whanau in a way that benefited the entire collective of this particular whanau.

The concept of whanaungatanga embraces much of the experiences that occurred within whanau during their experience of stroke. Whanaungatanga is all that activity that bonds and strengthens the whanau and arises out of the shared kinship and family responsibilities. It is interdependence and not independence as expressed by the actions of the individual whanau members. It is the aroha driven commitment by one whanau member towards another. The concept goes a long way to describing the actions of the son as related in the paragraph above.

The numbers of the whanau were very important and from their collective presence great personal comfort and strength was derived. This was particularly commented upon by the partners of the whanau member affected by stroke when he or she was facing those first days of the acute initial phase in hospital following the occurrence of the stroke event. It was also something that just seemed to happen without a spoken word. Whanau members just appeared and these ranged through all age ranges from mokopuna, tamariki, brothers and sisters, and elders of the iwi, hapu and whanau.

Upon discharge home it was very important for the whanau to have home life restored to what it was previously. This was seen as essential for the health and

wellbeing of the whanau, not just for the member affected by stroke. Tamariki and mokopuna who had been cared for by others whilst the member affected by stroke was in hospital were all brought home. For Maori there is great comfort and healing drawn from the collective of the entire whanau as expressed by one: "and being with the whanau; that was the most...the closeness." One wife pointed out, it was not home without the tamariki, but she also made the telling comment that as it could not be home without them, (the tamariki and mokopuna) what would have been the point of bringing her husband home? It was acknowledged by several wives and mothers that there were problems that arose from the tamariki and mokopuna not understanding the situation with their father and grandfather. It was also very clearly expressed though that having the husband, father and grandfather home without these young persons also was just not even considered.

### **Provision of services**

I have stated that Maori expectations of service and needs for information about services is no different than that of non-Maori. In considering the issues raised in this study, the context of service delivery needs to be considered in light of the service delivery changes that occurred within District Health Boards with the health reforms. These 'reforms' seem to have had a continuously evolving life of their own throughout the 1990's through to the present day. A discussion of these changes and how they effected Assessment, Treatment and Rehabilitation Service delivery in Taranaki has been given in Chapter 3. However whilst an understanding of these changes may well provide an explanation as to why some deficits in service delivery occur, this understanding does not excuse such deficits.

Criticisms, both direct and implied, as expressed through the reflections and memories of the whanau focus groups are placed within the context of the changes made as a consequence of the health reforms however it is clear that there is room for improvement and there needs to be a greater focus on service provision to Maori and all those who live in essentially rural areas. It needs to be noted that the criticisms of service delivery, availability of services, and access to services that arise from this study are not new revelations. Strong recommendations regarding these issues were made in the reports "He Anga Whakamana" (Ratima et al, 1995), "The Health and Wellbeing of Older People and Kaumatua" (MOH, 1997), "Oranga Kaumatua: The Health and Wellbeing of Older Maori People" (Te Puna Kokiri, 1997), "Reducing Inequalities in Health" (MOH, 2002), and "He Korowai Oranga: Maori Health Strategy" (MOH, 2002).

A common complaint was the arbitrary six-week cut off for service of rehabilitation physical services such as physiotherapy. This appeared to apply to all persons referred for ongoing rehabilitation following discharge but even then one is entitled to question the efficacy of a 20 minute session that occurred only once, perhaps twice a week? One whanau made an astute observation on this cut off of service. They felt that if physiotherapy had been continued beyond the six weeks then maybe their husband and father would have been doing more than he was now able to do. They continued on to express their feelings of inadequacy in undertaking ongoing therapy because "we are not professionals." The existing level of return of function in their husband and father was felt by them to be because they had not been able to do more for him. In an endeavour to gain reassurance that what they were doing was correct they went back to the General Practitioner who merely stated that: 'You are doing well on your own.'

Continuing rehabilitation services and/or supervision of the patient was seen by the whanau as being important for ongoing improvement and recovery of function. Current service delivery in Taranaki once a patient has been discharged from acute care at Taranaki Base Hospital consists of one outpatient rehabilitation clinic appointment per week for six weeks. There is no domiciliary community ongoing rehabilitation service delivery. This whanau confirmed for me that there would be a huge benefit to be gained from the availability of domiciliary supervision and education in the home of the whanau member affected by stroke. Evidence from rehabilitation units and ongoing research into stroke rehabilitation supports this reflection made by the whanau (Baskett, 1996; Weir, 1999; Koch & Holmqvist 2000, 2001; Rosenberg & Popelka, 2000).

In a situation where AT&R services are appropriately resourced a General Practitioner would be able to refer to the service to have the whanau member affected by stroke reassessed. There are only six specialist rehabilitation physicians in the whole of Aotearoa/New Zealand; the closest to this locality is at Mid Central Health in Palmerston North. All other AT&R services are supervised by Geriatricians or Physicians in various capacities, as is the case in Taranaki with a geriatrician supervising the rehabilitation service of the medical unit. The literature as cited above strengthens the arguments for ongoing individualised therapy and reassessment of that therapy. The published research proves recovery of function and independence of the person affected by stroke is related to the amount of therapy they receive (Baskett, 1996; Weir, 1999; Koch & Holmqvist 2000, 2001; Rosenberg & Popelka, 2000).

Another whanau seeking an explanation as to why post discharge service provision was limited to six weeks were given several conflicting reasons. The first two of these reasons appear to be unethical in that the whanau were supposed to accept and understand as justification for the cutting of services after six weeks, "waiting lists" and "lack of funding."

When one considers what can contribute to a "waiting list" it is first acknowledged that there must be a need for the service that is being unmet for this to occur. This leads to an examination as to why the service is not meeting the need? Are there enough therapists to give the treatments? If there were, then there would be no waiting list. If there are not, why not? Are there no therapists available through sick leave, annual leave, service demands elsewhere in the hospital, that have limited their availability to this service? Do established staffing levels not allow for cover to meet these unexpected eventualities and enable the continued meeting of service expectations? Is there enough funding to employ the available therapists needed to run an efficient service that meets the need? It is not possible for someone outside the employ of the Taranaki DHB and it's management to answer these questions however the answers probably lie within the context of the conflict between professional and service reporting functions that saw allied health personnel such as physiotherapists taken away from direct reporting to the 'head' of the rehabilitation service. The questions also need to be considered in the context of the reforms that occurred in Taranaki as a result of the health reforms of the 1990's discussed earlier in this thesis. These should not be used as the reason that adequate discharge service provision cannot be provided. The apparent policy of one appointment per week for six weeks then cessation of follow up with no domiciliary service requires examination.

The second justification this whanau was given for non-continuance of service after six weeks was that their loved one had not made enough progress. The implication of this statement was that others (on the waiting list) might benefit. This is be an indictment of the service itself and not the whanau member affected by stroke or the members of the whanau. The whanau is entitled to observe, as it did do, on the efficacy of a physiotherapy session that lasted 20 minutes once a week. Those experienced in the art and practice of rehabilitation are aware that individual rehabilitation programmes cannot be made to adjust or fit into a designated time frame. The literature (Baskett, 1996; Weir, 1999; Holmqvist & Koch, 2000) supports the belief that a physiotherapy session once a week is almost totally ineffective. Each and every individual will chart their own

progress and the empathetic, experienced rehabilitation health professional will take this into account, along with current service provision, before making such arbitrary statements such as "not made enough progress."

A further whanau who questioned the six week cut off for therapy post discharge were first of all given the reason that the service had a long waiting list. When the wife told them that that was their problem and not hers they then expected her to accept the reason that they did not have enough funding. Attempting to justify the lack of continuance of service provision, no matter how little it was, because of lack of funding is, in my belief, unacceptable. This is not an issue the patient is responsible for, and it is not a justification for terminating service provision so that some other patient may be brought in off the waiting list. The service provision is inadequate. Once again I heard a whanau stating quite firmly that it was their belief that their stroke affected member would be "a hell of a lot further on" than he was if he had been able to have continual physiotherapy.

The issue of ongoing rehabilitation service provision after discharge is one that needs examination by the Taranaki District Health Board. It would appear that in the current climate of fiscal restraint across the public sector and the requirement to live within their allocated funding the Board has set itself priorities and allocated funding to services according to those priorities. It is believed that further research would identify the unsatisfactory situation of unmet ongoing needs of the disabled in Taranaki. It is my belief that the inadequacy of service provision affects both urban and rural residents of Taranaki. An adequately resourced research study would identify the burden of unmet need and the potential for a higher quality of life of those affected by stroke and other disabling situations. Such a study could lead to the resetting of priorities to meet unmet needs.

### **Provision of information related to services**

A stroke event is a sudden and catastrophic event. It strikes the family completely unawares. It causes confusion, turmoil, anguish and upheaval in their lives. In the initial stages many of the whanau referred to "things going over their heads" and just not understanding what was said to them. However as the average length of stay in the hospital environment was six weeks it is believed that the stresses and pressures of those initial days would have been reducing as discharge approached. The whanau members would have been more receptive and understanding of what they were told as they prepared for the discharge

home of their loved one. One wife quite candidly stated that whilst she had education and information sessions given to her she did not remember any of it now. This would appear to indicate a need for more information to be given in written form so to be used as a future reference source for the whanau. Upon reading the transcripts and reflecting on the taped interviews it is an obvious conclusion that in some cases the information given to whanau was deficient in its detail or totally absent. Whether this was a deliberate action or one of oversight is not known and no judgement is therefore made on this absence of information.

The longest delay in the provision of information related to one whanau whereby 18 months following discharge from the hospital the wife found out that she was entitled to have her husband referred to the Orthotics Department of the local hospital to obtain some specially made footwear. This occurred during the focus group interview. At the same time it was also revealed that the wife was unaware of the ability to have a referral for podiatry services made. She had expressed unhappiness at cutting her insulin dependent diabetic husband's toenails. As health professionals are aware, foot care of the insulin dependent diabetic is a crucial and vital factor in their care. When her husband suffered the residual mobility difficulties associated with his stroke foot care should have been a high priority for the education instruction of the whanau prior to discharge. These two deficits in information and resulting service provision were rectified by the intervention of the Maori Disabilities Advocate and appropriate referrals were made. Finally for this whanau was the need for a ramp that the Maori Disabilities Advocate was able to rectify when Occupational Therapy had deemed it "not necessary."

Another issue around service provision that arose during this study was that a recommendation for service provision by an 'arm' of the hospital and disability services, such as the Services for the Elderly, or the AT&R Service, is not accepted by the local NASC agency. Based in New Plymouth this agency is Access Ability. They (Access Ability) have this requirement, probably in their operating contract requirements, to revalidate all needs assessments that have been performed before they will provide services (personal communication, 22 September, 2002). This is an undisputed waste of time, resources and finances and often results in a number of days delay before essential services and support needs are met.

Reference has been made to the patience and tolerance of Maori and how whilst pointing out deficits they were most keen not to be seen to be laying blame on

health workers. Time after time in regards to service and information deficit, allowances were made by Maori. I have commented earlier that services need to be tailored to the actual needs of the whanau. This does not just apply to writing new operating procedures but to also allow a flexibility that at present is not allowed. A perfect example of this is the inability of the Home Help to actually do what is needed in the home, to meet unmet needs, because a particular task is not contained in the job description of the Home Help.

One very proud lead carer wanted to have the fridge pulled out so she could vacuum behind it but the Home Help was forbidden to do that by her job description. The carer ended up not utilising the services of Home Help that would have eased her burden of care because they could not do what she wanted. She stated that they only seemed able to do those things she could do for herself such as vacuum the floors and hang out the washing. This is an example of the problems caused by the inflexibility of the current configuration and operating instructions that govern the work of Home Help in Taranaki and possibly Aotearoa/New Zealand. These situations would not be unique to Maori and this is acknowledged.

The provision of respite care whereby the whanau members would be able to leave their partner well cared for while they went and stayed overnight on a marae for a function such as a tangi or to attend an important hui was also an unmet need. Such participation in the life of the Maori community was impossible unless a family member could fill in and allow the lead carer to go away. These issues have been previously discussed as unnecessarily confining a whanau member or their carer to home, even though being at home is so important to the whanau member affected by stroke and their lead carer. It is very important for the whanau member affected by stroke to be at home but not confined to home. Due to the lack of flexible carer relief services the whanau lead carer ends up being confined to the home in addition to their loved one.

This confinement seriously impedes the ability of the whanau member affected by stroke and their lead carer to participate in the life of their marae. The need to participate in marae life and issues affecting the wider Maori community is extremely important to the cultural integrity of Maori and is one that is not widely acknowledged by the essentially mono cultural Pakeha dominated service providers discussed or encountered in the course of this study. It is hoped that a more culturally sensitive service provision might be enabled in the future that will suit the needs of Maori. As stated previously, it is believed that a more

flexible, responsive service needs provision need not cost any more than the current service that does not meet the needs of whanau.

### **Expressed need for Maori based services**

One whanau during the focus group interview clearly identified that there was a need for Maori based services. At the same time this whanau did not want to be seen as condemning the health service workers that were available. The wife in this whanau quite passionately stated that there was not enough people 'out there' to do the work and she acknowledged that this frustrated her. She knew what was required to assist her husband to progress but recognised it was all a dream because of the lack of service providers and therefore health workers, Maori or pakeha.

This same whanau then pointedly described the efficiency, helpfulness, obliging, accommodating, supportive and caring interactions they had with the He Whakaruruhau Trust and the Maori Disabilities Service Advocate. This is the only Maori Service Provider working in the field of disabilities and its activities were really appreciated. It would seem that this is a service that listens, and makes genuine attempts to meet identified needs. The fact that it succeeds is probably the reason the wife states that she 'loves them!' Listening to her tell of the interactions she has had on the telephone with their office staff, and observing her interactions face to face with the Maori Disabilities Advocate, one can see the difference between conventional mono cultural services and those that are Maori.

In a historical context the He Whakaruruhau Trust was established following the time that this whanau's experience of stroke began. The whanau lives some 42 kilometres south of New Plymouth in the rural town of Stratford. The small hospital that served this town and district was closed as part of the health reforms that have been described, and replaced by a clinic. A further 28 kms on is a larger town, Hawera, which has a small hospital of 20 beds and a small rehabilitation outpatient service. It is only the outreach of the Trust that has brought service and the knowledge of service availability to many families affected with disability in rural Taranaki.

The provision and coordination of services for the disabled, from what ever means in essentially rural Taranaki, needs urgent and careful study. One of the 'Key Players' during interview for this study made a suggestion that has considerable merit. It was suggested that various voluntary organisations

working in the area of disability, such as the Stroke Foundation, should have built into the Job Description of their Field Officer (and salary provision provided to them), the role of needs assessment and service co-ordination. The significant part of this was that Access Ability would then accept the recommendations made and provide service and/or supplies without revalidation for 6 months. It has been explained that the existing requirements for Access Ability to revalidate all needs assessments before services can be provided often leads to unacceptable but inevitable delays.

The opportunity for a specific Maori Needs Assessor, which could lead onto specific service provision under the umbrella of the Taranaki MDO (Tui Ora Ltd) would be an exciting challenge and opportunity for Maori. The functioning of this person/s would have to be able to begin with the patient in hospital for the concept to function effectively. This need not cost any more than the current monies spent on needs assessment and service coordination providing the functions of the existing multiple service providers were rationalised by being centralised into the job description of this one person.. The functions of needs assessment and service co-ordination for Maori could well sit comfortably within the existing He Whakaruruhau Trust's activities.

### **The interface between traditional/non-traditional methods of caring**

A secondary aim of this study that arose from the primary research question was whether there was any information identified that might enhance the partnership between traditional and non-traditional care as experienced by Maori whanau. From the accounts of whanau of the importance of taha Maori and all that that involved, along with cultural practices such as karakia and mirimiri, I am left with an overwhelming sense of the importance of acute and rehabilitative hospital services to have an open mind and acceptance of the traditional holistic comprehensive ways of Maori.

Reference has been made several times in this thesis to concepts of health. The terminology "models of health" arises from a westernised medicalised approach to health care. Whare Tapa Wha, Te Wheke, and others are some of a number of Maori expressions of hauora, which encompass more than just the physical aspects of the contributors to the health of the individual. They are models of hauora and well being for the entire whanau. Over and again during this study the comprehensive intertwining of the concepts of wairua, hinengaro, tinana and whanau, the whenua, and te reo, were unspoken but emphasised by whanau as

they spoke their stories and related their experiences. These concepts were central to their lives. They were, and are, a lived experience.

Hospital service care provision has to more readily accept that a group of relatives and immediate whanau will often be the norm. Whanau will come, and will need to be in the same room as their whanau member affected by stroke. The placing of a seriously ill Maori in any multi patient bedded room is fine if that is all the bed space the ward/unit/hospital has available at that time. However the needs of the whanau must be considered and consideration given to moving the whanau member to a single room situation as soon as bed space demands and priorities allow. Acknowledging the importance of karakia performed regularly by whanau should enable this privacy of a single room to occur sooner rather than later.

We have had one stated example whereby medical staff took an interest in the practice of mirimiri as performed by the wife of the stroke victim and this appears to have had a positive benefit to the patient. This is an excellent example of cooperation with Maori and integration of traditional and non-traditional methods of care. These non-traditional (for our mono cultural health services) methods of caring and treatment must be allowed to be incorporated into the comprehensive individualised care plan of the whanau member affected by stroke. The importance of this concept for our hospital and community services is that the western medicalisation model of care actually has to relinquish its dominance in the determining of the care in dealing with whanau devastated by stroke, or any other catastrophic disabling illness or accident. A realisation of this, and a commitment to it, by these services will enable comprehensive, holistic and culturally appropriate services to be delivered to Maori in general and whanau specifically. The He Whakaruruhau Trust offers an excellent example of a community based appropriate sensitive service model for Maori and the persons who live in our rural communities.

### **Enrichment of the experience of stroke**

A further secondary aim of this study was to identify any information that might enrich the experiences for whanau caring for a member affected by stroke. Many of the whanau interviewed for this study had pertinent information and reflection they wished to pass on to others. Much of this reflection was personal and contained within the whanau however some of it related to external influences and forces. I offer that advice for the future benefit of other whanau experiencing the devastation of stroke in their lives.

Stroke causes a disruption in peoples lives that appears incomprehensible to those who face it. Many whanau stated that the partners needed to be strong and to reach inside themselves and to not forget their karakia. The supporting and nurturing functions of whanau were recalled as the advice was offered to not forget the whanau. The whanau offers love and support that if not there makes coping that much harder for the partner. A caution was also expressed that if help was not asked for it would not be forthcoming. This particular speaker went on to express how foolish it was to say to yourself: 'I can manage.'

Building on all the good things that they have done together in the past allows the partner to make things as normal as possible for their loved one affected by stroke. This piece of advice was made recognising that it was hard at first, but was seen as crucial in re-establishing relationships and the change in relationships that was the result as a consequence of the stroke event. Very strong statements were made for whanau to insist, almost demand, services and information from the hospital before discharge. One whanau even reminded whanau so affected to remember their iwi as this should be a source of strength and support in these matters. It was clear that many whanau members acknowledged that they just did not have the information, but perhaps more telling, they did not have the knowledge to ask for it.

## **Conclusion**

This thesis has explored the whanau experience of stroke. Seven whanau groups willingly participated to tell their story of the experiences they had shared of the devastation that stroke can bring. With passion and emotion they relayed how their lives had been changed forever and how they were still coping and coming to terms with the stroke event.

In examining the broad brush of the "experience" of stroke for Maori one has to acknowledge the defining differences between Maori whanau and non-Maori families. The whanau has a nourishing and nurturing role that is integral to its function in a way that non-Maori families do not have. There is a spiritual dimension and a caring that is expressed at a different and higher level with Maori. It is this expression of caring, this manaakitia, that makes what whanau do in caring for their member affected by stroke or other devastating disabling illness or injury, and indeed each other, so special. It is perhaps best summed up with the term whanaungatanga. From the moment the whanau became aware that a stroke had occurred there was always someone from the whanau,

usually the partner, with the affected whanau member at all times. Other whanau members were usually always present also in support of the stroke affected member but also in support of his/her partner. It is important to acknowledge that Maori are a diverse group of people and that with urbanisation there may not always be that maintenance of ongoing support and nurture that was seen in the whanau that contributed to this study.

Whanau were ready and willing to learn the hands on personal cares of their loved one and often this occurred by a process of observation. They were there and simply observed, absorbed and repeated, what they saw staff undertaking. Exceptions to this occurred with the whanau unfortunate enough to have a whanau member affected by stroke in Australia. Their hospital experience was a negative one both in the patient being allowed to do things (ie: to regain independence), the relatives not being allowed to learn cares, and for the total disregard of any considerations of cultural difference.

Dissatisfaction has been expressed by nearly all the whanau groups over the automatic cut off of post discharge of continuing therapy and service provision at six weeks. There was also dissatisfaction at the level of therapy, that was provided and a number of whanau commented that it appeared they were expected to function at the level of the trained professional. Yet these same whanau were not adverse to continuing therapy at home, they just needed (presently non-existent) supervision that they were doing it correctly. Whilst there were only seven whanau groups in this study the incidence of delayed, deficient, and inactivated needs assessments and service provision is too high to indicate the operating of an efficient service. Indeed in one case the wife waited four years for hand rails adjacent to the steps to be installed.

The importance of the holistic Maori worldview, *te Ao Maori*, is clearly highlighted and shines through in the stories told by whanau as they referred to a *taha Maori* perspective in their experience of stroke. *Taha Maori*, *karakia*, *mirimiri*, and the knowledge derived from their *tipuna* was so much part of their lives, it was a lived experience. The attachment and importance of these facets of the life force, the *mauri* of the individual, was unable to be separated from the lived experience of the whanau members. The whanau who participated in this study would best be described as traditional whanau with all their members being of the same descent group. The experiences they related might well have been different with a more modern urbanised whanau that had left their whanau supports behind them. It is pleasing to report that in all cases the whanau were facilitated in aspects of their cultural values and beliefs while their loved one was

in hospital and only the utmost consideration was shown to them in all but the one instance here and in Australia. It is believed that hospital managements need to consider the appropriateness of the imposition of personal care by all male bathing and lifting orderly teams on female elderly Maori.

The importance of Te Reo has taken on a new meaning for me and as a result I have to question the efficacy of Speech Language Therapy performed by non-Maori. It would seem that speech language therapy to be really effective needs to be undertaken in the first language of the patient. In the cases discussed in this study it was affirmed that it was only when Te Reo was used did the whanau member affected by stroke demonstrate gains in recovery.

In conclusion it bears repeating that a number of the recommendations made below have been made before in more than one significant Government initiated document. Nonetheless the recommendations are valid for their repeating as they have arisen out of this study into the experience of whanau caring for members disabled from the effects of stroke in Taranaki.

Recommendations for practice, and the rationale for making these recommendations, that arise from this study are:--

- (1) That a review of the present post discharge therapy service provision be undertaken

*Rationale:* It is difficult to ascribe the "best practice" label to currently provided post discharge services available to Taranaki whanau and families and the whanau member affected by stroke when service and therapy provision is cut off at 6 weeks post discharge.

- (2) That the scheduled appointments per week in the post discharge therapy provision be reviewed

*Rationale:* Reference to the literature from the fields of current rehabilitation practice will repeatedly confirm that optimal continued recovery of function following stroke will unlikely be achieved with only one therapy session per week.

- (3) That urgent consideration be given to the provision of community based supervision of service and therapy for families and whanau with a disabled individual at home

*Rationale:* It is recognised that the health budget for service provision is finite, however it is also acknowledged that whanau and families will willingly undertake elements of continuing therapy for their loved one. To do this effectively they need regular on-going supervision by a domiciliary health professional to monitor progress and amend rehabilitation programmes as function is recovered.

- (4) That the operation of the multidisciplinary team in its totality be reviewed and operational improvements be introduced

*Rationale:* There appears to be no planned education for the delivery of safe personal cares to whanau and families of the whanau member affected by stroke while in the hospital. The considerable delays in the implementation of Occupational Therapy reviews and implementation of recommendations would tend to indicate that there is no adequate case management for any individual. There certainly does not appear to be any means to ensure that services are, or have been provided, or that a progression of care has been advanced.

- (5) That appropriately accredited health professionals have their needs assessments and recommendations implemented without the requirement for further revalidation within 6 months of the demonstrated need

*Rationale:* There presently exists a process that wastes time and resources when needs assessments made by competent personnel are required to be revalidated by the local NASC agency before services can be implemented.

- (6) That consideration be made to accrediting, following appropriate assessment, suitable field officers from voluntary organisations (such as the Stroke Foundation) to conduct accurate and reliable needs assessments that will be accepted without revalidation for six months by the local NASC agency

*Rationale:* Field Officers, many of them trained health professionals, of these agencies are well placed to accurately assess the needs of the patient yet currently any recommendation made is required to be revalidated before

what may be essential services are put in place. This has resulted in considerable delays for some whanau and families.

- (7) That the present functioning and delivery of carer relief be reviewed with a view to permitting more flexibility in its administration

*Rationale:* The present inflexibility of the provision of carer relief does not meet the needs of whanau. There needs to be the allowance for overnight stays that will permit the lead carer to attend to Maori cultural needs such as tangi and hui.

- (8) That the present inflexible delivery of home help be reviewed to permit a wider range of tasks to be performed in the home of the whanau/family

*Rationale:* It would appear to be a waste of time and resources to have home help sent into a home and restricted to doing only those tasks able to be managed already by the whanau/family

- (9) That an urgent study be undertaken to determine how a reliable, regular and reasonably costed public transport service can be provided to the whanau member affected by stroke and their family in rural Taranaki

*Rationale:* Access to services is presently denied those who live in rural areas due to the lack of such a transport service.

- (10) The appropriateness of the imposition of personal care by all-male bathing and lifting orderly teams on female elderly Maori needs to be reconsidered

*Rationale:* For older Maori women this practice is offensive and culturally inappropriate.

- (11) That consideration be made to undertaking further research based on the findings of this study

*Rationale:* A number of issues have arisen that are deserving of further research to substantiate and verify the findings of this study. These could include:

- A parallel study of non-Maori families experience of stroke

- A study into the efficacy of domiciliary rehabilitation services
- A study into the provision of more efficient and cost practical transport services to rural Taranaki
- A study into the more efficient operation of the multi disciplinary team of rehabilitation services

## **APPENDICES**

- 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 Massey University human Ethics Committee approval, June 6, 2002
- 7 Massey University human Ethics Committee approval, June 27, 2002
- 8 Taranaki Regional Ethics Committee approval, May 2, 2002
- 9 Te Whare Punanga Korero approval, May 1, 2002
- 10 Tui Ora Ltd letter of support, March 25, 2002

## Appendix One

### The History of Pukerangiora

Pukerangiora lies on the banks of the Waitara River eight kilometres inland from the river mouth. It is a high cliff on a bend in the river and forms a strong defensible position and a hapu of the Te Atiawa Iwi used this site for their pa. Pukerangiora was said to be the strongest fortress of the Te Atiawa after Ngamotu. It is said the name came from the fact that the hill leading up to the cliff was previously covered with the rangiora shrub.

In 1822 a large party of Waikato were besieged by the Atiawa peoples as they were endeavouring to return to their homelands following a journey that went as far south as the Cook Strait. The Pukerangiora hapu actually assisted the Waikato throughout a seven month long siege by sheltering them in their pa – Pukerangiora. A party of 2000 Waikato under Te Wherowhero came to the aid of their people. Severely mauled by the local Atiawa, the survivors linked up with their tribesmen besieged at Pukerangiora and the combined party was allowed to return to the Waikato unmolested.

The Waikato never forgot the defeat of their relief party and in December 1831 a raiding party said to consist of nearly 4000 Waikato led by the chief Te Wherowhero raided down into the Waitara area. They seized, slew, and ate a number of the local population which caused a panic and the local people quickly retired to their pa without the precaution of bringing in provisions to withstand a siege. The enemy laid siege to Pukerangiora for twelve days, and all their attacks were driven off. However hunger finally drove some of the inhabitants to attempt to evacuate the pa in daylight. The enemy caught and killed many of these local people.

With this example before them when the enemy finally captured the pa, many of the defenders threw themselves off the cliff so to avoid the fate that awaited them in the hands of their enemies. Many of the local Maori women threw their children over the cliff, jumping after them to avoid the fate that was to be that of those that were captured. So many jumped that it is said that some had their fall cushioned by the bodies of those already fallen and they survived.

The Pukerangiora inhabitants had every reason to fear their fate. All survivors were slaughtered in a terrible manner and it is said that some of the Waikato died of gluttony they ate so much of their conquered. The Waikato chief Te Wherowhero is said to have killed 150 with his own mere.

Pukerangiora was never reoccupied and is today one of the most sacred sites to the Te Atiawa and Taranaki peoples. (Rawson, 1990; Wells, 1976).

# Appendix Two

## Proposal as submitted for Ethics Committee approval

EA 05/99  
Page 1

### NATIONAL APPLICATION FORM FOR ETHICAL APPROVAL OF A RESEARCH PROJECT

#### PART I : BASIC INFORMATION

Protocol number and date  
received (for office use only)

1. Full project title

Stroke rehabilitation in Maori: A qualitative study into the experiences of whanau caring for a member who is disabled by the effects of a stroke.

2. Short project title (lay title)

Stroke Rehabilitation in Maori – A descriptive study.

3. Lead Principal Investigator's name and position

Andrea Michael Corbett, Course Co-Ordinator, Dept of Nursing and Science, Western Institute of Technology at Taranaki

4. Address of lead Investigator

C/- WITT

Dept of Nursing and Science

PO Box 2030

New Plymouth

Work ph

Emergency No.\*

Fax

E-mail

5. Lead investigator's qualifications and experience in past 5 years (relevant to proposed research)

RGON -- Registered General and Obstetric Nurse

BN -- Bachelor of Nursing

Dip Rehab – Post Graduate Diploma in Health Science – Rehabilitation (Otago)

Dip Managed Care – Post Graduate Diploma in Health Science – Managed Care (Auckland)

1997 – 1998 Registered Nurse, Rehabilitation Service, Waikato Hospital

1998 – 2000 Clinical Resource Nurse, Assessment Treatment and Rehabilitation Service, Health Waikato

2000 – 2001 Clinical Nurse Leader, Assessment Treatment and Rehabilitation Service, Wairarapa Health

2001 – present Course Co-Ordinator, Department of Nursing and Science, Bachelor of Nursing programme, Western Institute of Technology at Taranaki, New Plymouth.

6. Co-investigators' name(s) and position(s)

A Not Applicable

B

C

D

7. Address of co-investigator A

N/A

Work ph

Emergency No.\*

Fax

E-mail

N/A

8. Address of co-investigator B

N/A	Work ph	N/A
	Emergency No.*	
	Fax	
	E-mail	

9. Address of co-investigator C

N/A	Work ph	N/A
	Emergency No.*	
	Fax	
	E-mail	

10. Address of co-investigator D

N/A	Work ph	N/A
	Emergency No.*	
	Fax	
	E-mail	

11. Where this is supervised work

- 11.1 Supervisor's name
- Position
- Day time phone number

Dr J. Boddy, Professor of Nursing
School of Health Sciences
Massey University - 06 350 5799 ext 2541

- 11.2 Signature of supervisor (where relevant)
- Declaration: I take responsibility for all ethical aspects of the project

--

12. List any other New Zealand Ethics Committees to which this project has been submitted and attach their letters of approval where available

Massey University Human Ethics Committee.
Approval letter will be forwarded from the Taranaki Regional Ethics Committee to the MHEC.
Approval letter will be forwarded from the Massey Human Ethics Committee to the TREC

13. I wish the protocol to be heard in a closed meeting  
(If yes the reason should be given in a covering letter)

Yes       No

14. I request a fast track procedure

Yes       No

- 15. Proposed starting date (dd/mm/yy)
- 16. Proposed finishing date (dd/mm/yy)
- 17. Duration of project (mm/yy)
- 18. Proposed final report date (mm/yy)

20/05/02
21/02/03
10 months
March 2003

## PART II : PROJECT SUMMARY

### 1. Multicentre proposals

*(Important: read the guidelines, Appendix 1)*

- |  |                                     |     |                                     |
|--|-------------------------------------|-----|-------------------------------------|
|  | Yes                                 |     | No                                  |
| 1.1 Is this a multicentre study? (if no, go to question 2)   | <input type="checkbox"/>            |     | <input checked="" type="checkbox"/> |
| 1.2 If yes, name the primary ethics committee?   |                                     |     |                                     |
| If no, name the primary ethics committee   | Taranaki Regional Ethics Committee  |     |                                     |
| 1.3 Has the protocol been submitted to any other ethics committees in New Zealand? (If yes, attach copies of relevant correspondence)        | <input checked="" type="checkbox"/> |     | <input type="checkbox"/>            |
| 1.4 Who is the lead investigator or institution in New Zealand?  | N/A                                 |     |                                     |
| 1.5 List the other New Zealand centres involved, and the Principal Investigator for each centre  | N/A                                 |     |                                     |
| 1.6 Has the Principal Investigator(s) from secondary sites agreed to participate? (attach copies of signed Part V Declaration for each site) | <input type="checkbox"/>            | Yes | <input type="checkbox"/> No         |
|  | N/A                                 |     |                                     |
| 1.7 If the study is based overseas, what other countries are involved?   | N/A                                 |     |                                     |
| 1.8 Does this research involve any genetic testing?<br>If yes, complete section.....   |                                     |     |                                     |

### 2. Scientific Assessment

- |   |                          |     |                                     |    |
|---|--------------------------|-----|-------------------------------------|----|
| Has this project been scientifically assessed by independent review?              | <input type="checkbox"/> | Yes | <input checked="" type="checkbox"/> | No |
| If yes, by whom? (name and position) A copy of the report should also be attached | N/A                      |     |                                     |    |
| If no, is it intended to have the project scientifically assessed, and by whom?   | No                       |     |                                     |    |

### 3. Data and Safety Monitoring Board (DSMB)

- |  |                          |         |                                     |     |
|--|--------------------------|---------|-------------------------------------|-----|
| 3.1 Is the trial being reviewed by a data and safety monitoring board? | <input type="checkbox"/> | Yes     | <input checked="" type="checkbox"/> | No  |
| If yes, who is the funder of the DSMB?                                 | <input type="checkbox"/> | Sponsor | <input type="checkbox"/>            | HRC |

### 4. Summary

Give a brief summary of the study (not more than 200 words, in lay language)

It appears to be an unsatisfactorily unanswered question as to why so few Maori whanau access rehabilitation services following stroke. The whanau just gets on with it. Is this a deliberate choice to ignore what are essentially pakeha staffed services? Is there a fundamental belief that they will care for their own without assistance? Is the whanau aware of the services available to them? What are the extra demands of care placed upon them because they do "make do?"

With the greater incidence of risk factors leading to stroke among Maori, developing an understanding of the experiences of whanau in dealing with a family member with stroke the study may yield useful information. This understanding of the experiences of the whanau could lead to an enriching of those experiences and may enhance the partnership between traditional and non-traditional care as experienced by Maori whanau.

## PART III : PROJECT DETAILS

### SCIENTIFIC BASIS

#### 1. Aims of Project

##### 1.1 What is the hypothesis/research question(s)? (state briefly)

What is the experience of the whanau in caring for a member affected by a stroke.

##### 1.2 What are the specific aims of the project?

1. To develop an understanding of the experience of whanau in caring for a member disabled by the effects of stroke.
2. To identify any information that could lead to an enrichment of the experiences of the whanau caring for a member disabled by the effects of stroke.
3. To identify any information that may enhance the partnership between traditional and non-traditional care as experienced by Maori whanau.

#### 2. Scientific Background of the Research

Within a qualitative framework a descriptive study using focus groups and key informant interviews will be undertaken. This approach has been adopted because it is the intent of the researcher to elicit perceptions and some understanding of the Maori experience of stroke, rather than imposing those that arise from her own experiences as a health professional working within the discipline of rehabilitation practice.

Descriptive studies are stated to often represent the first scientific toe in the water in new areas of enquiry. It is further stated that a fundamental element of descriptive reporting is a clear, specific, and measurable definition of the disease or the condition in question. Like newspapers, good descriptive reporting answers five basic W questions: who, what, why, when, where . . . and a sixth implicit question: so what?

The who, what, why, when and where of stroke as it affects Maori are reported in the epidemiology and other health statistics released periodically by the Ministry of Health. To answer the "so what?" question it is believed that within the whanau caring for the stroke affected whanau member there are meanings and values to be discovered. It is through the use of focus groups and key informant interviews that it is hoped these meanings may be uncovered for the betterment of others.

##### Key References:

"Indicators of Inequality: Classification and Selection of Ethnic Health Disparity Indicators." Public Health Intelligence Occasional Bulletin No 5, MOH, 2001.

"Priorities for Maori and Pacific Health: Evidence from Epidemiology." Public Health Intelligence Occasional Bulletin No 3, MOH, 2001.

"Whaia Te Whanaungatanga: Oranga Whanau. The Wellbeing of Whanau: The Public health Issues." MOH, 1998.

"Maori Access to health Care." NZHTA, 2001

"Effectiveness of Assessment, Treatment and Rehabilitation." NZHTA, 1999

"Rehabilitation of Cerebrovascular Disorder (stroke) Early Discharge and Support." NZHTA, 1999

"Our Health, Our future: The Health of New Zealanders 1999." MOH, 1999.

**3. Participants**

3.1 How many participants is it intended to recruit?

The immediate whanau of the selected stroke patients. The stroke patient will also be invited to take part.

A minimum of six whanau groupings will be enrolled in the study.

3.2 How will potential participants be identified?

By the local North Taranaki Iwi and staff of the Maori Development Organisation – Tui Ora Ltd.

By South Taranaki Iwi, Ngati Ruanui Health Centre staff

3.3 How will participants be recruited? (e.g. advertisements, notices)

By direct contact by Tui Ora community health workers and/or Makere Wano.

By Ngati Ruanui Health Centre staff

3.3.1 Where will potential participants be approached? (e.g. outpatient clinic) If appropriate, describe by type (e.g. students)

In their own homes or by other suitable method.

3.3.2 Who will make the initial approach to potential participants?

Community health workers of Tui Ora Ltd  
And/or Makere Wano.

By Maori Health workers of Ngati Ruanui Health Centre

3.3.3 Is there any special relationship between the participants and the researchers? e.g. doctor/patient, student/teacher

None

3.4 Briefly describe the inclusion/ exclusion criteria and include the relevant page number(s) of the protocol or investigator's brochure

Exclusion criteria: Being non-Maori

Inclusion criteria: A whanau grouping that identifies as Maori with a family member who has had a stroke in the past 6 to 12 months, and agrees to participate.

3.5 If randomisation is used, explain how this will be done

N/A

#### 4. Study Design

4.1 Describe the study design. Where this space is inadequate, continue on a separate sheet of paper. *Do not delete page breaks or renumber pages.*

This will be a descriptive study within a qualitative study framework.

The whanau group will become a "focus group" for the purposes of the study and will assemble at a venue of their choosing. The researcher will be present however the focus group discussion will be facilitated by a community health worker from Tui Ora Ltd or a local Taranaki Maori Kuia, Makere Wano. Each whanau will be asked to identify someone to be classified as a key informant, anticipated to be the lead care giver of the stroke patient for further interview of a semi-structured open-ended question format.

These interviews will be audio taped, transcribed and the transcript returned to the whanau key informant for comment and/or editing as requested.

4.2 How many visits/admissions of participants will this project involve? Give also an estimate of total time involved for participants.

Focus groups of 2 to 3 hours duration.

Key Informant interviews 1 to 2 hours.

4.3 Describe any methods for obtaining information. Attach questionnaires and interview guidelines.

Observation and immediate recording onto note pad.

Audio recording of focus group discussion and of semi structured interviews with key informants. Questions for the key informant interviews will be raised during the focus group discussions.

4.4 Who will carry out the research procedures?

Andrea Corbett with assistance from Kuia Makere Wano, Bev Gibson, of Tui Ora Ltd, and other nominated Maori community health workers in North Taranaki.

Andrea Corbett with assistance of Suzanne Carr of Ngati Ruanui Health Centre, and other nominated Maori community health workers in South Taranaki.

4.5 Where will the research procedures take place?

In a venue agreed upon by the whanau.

Such venue might be the Rangiatea campus of the Maori Studies Dept of WITT, the Kopa Manaaki room at the Bell Street campus of WITT, or an appropriate marae setting. The home of the whanau will be used if that is their wish.

8. Address of co-investigator B

N/A

Work ph  
Emergency No.\*  
Fax  
E-mail

N/A

9. Address of co-investigator C

N/A

Work ph  
Emergency No.\*  
Fax  
E-mail

N/A

10. Address of co-investigator D

N/A

Work ph  
Emergency No.\*  
Fax  
E-mail

N/A

11. Where this is supervised work

- 11.1 Supervisor's name  
Position  
Day time phone number

Dr J. Boddy, Professor of Nursing
School of Health Sciences
Massey University – 06 350 5799 ext 2541

- 11.2 Signature of supervisor (where relevant)  
Declaration: I take responsibility for all ethical aspects of the project

--

12. List any other New Zealand Ethics Committees to which this project has been submitted and attach their letters of approval where available

Massey University Human Ethics Committee.
Approval letter will be forwarded from the Taranaki Regional Ethics Committee to the MHEC.
Approval letter will be forwarded from the Massey Human Ethics Committee to the TREC

13. I wish the protocol to be heard in a closed meeting  
(If yes the reason should be given in a covering letter)

Yes       No

14. I request a fast track procedure

Yes       No

15. Proposed starting date (dd/mm/yy)

20/05/02
----------

16. Proposed finishing date (dd/mm/yy)

21/02/03
----------

17. Duration of project (mm/yy)

10 months
-----------

18. Proposed final report date (mm/yy)

March 2003
------------

- A. If the method of analysis is **wholly or partly qualitative**, briefly describe the analysis. If interviews are to be used include the general areas around which they will be based. Copies of any questionnaires that will be used should be appended.

Focus group whanau discussions will be audio taped recorded and transcribed.

Following transcription of audiotapes, data will be analysed to identify themes until all themes are identified.

Semi structured interviews with key informants will be held following the focus group meetings. The questions to be used at these key informant interviews will be derived from the body of the conversation and discussion of the whanau focus group. (Hence it is not possible to attach a copy of a possible questionnaire).

Observational data will be added to the identified themes.

The overall approach to analysis of data arising from the focus groups and key informant interviews is that of content analysis. This approach identifies themes and patterns from each transcribed focus group and interview with key informants. These themes and patterns are inter-related with the transcripts of every other focus group and key informant. This approach enables the major themes arising from each transcription to be connected with each other. These themes will be formulated, the patterns described, and their possible meaning discussed. These discussions will be supported by relevant quotations from participants to support the data from which the patterns and constructs arise.

## 6. Risks and benefits

- 6.1 What are the benefits to research participants of taking part?

A sharing of their experiences in having a family member affected by stroke.

- 6.2 How do the research procedures differ from standard treatment procedures?

Research procedures do not differ.

- 6.3 What are the physical or psychological risks, or side effects to participants or third parties? Describe what action will be taken to minimise any such risks or side effects.

Use of a venue of the whanau's choosing will eliminate the possibility of distress that could occur with having the principal researcher in the whanau home.

Having a respected community health worker known to the whanau or a respected kuia as facilitator to lead the telling of the whanau experience, will also assist in lowering the risk of potential psychological distress to the participants.

- 6.4 What arrangements will be made for monitoring and detecting adverse outcomes?

There will be provision made for follow up counselling if emotional distress becomes apparent during the course of the focus group interviews, through a designated Maori counsellor or social worker.

- 6.5 Will any potential toxins, mutagens or teratogens be used?

Yes

Nov

If **yes**, specify and outline the justification for their use

6.6 Will any radiation or radioactive substances be used? Yes No

*Note: If any form of radiation is being used please answer the following. If no, go to question 6.8*

6.6.1 Under whose license is the radiation being used?

6.6.2 Has the National Radiation Laboratory (NRL)  
risk assessment been completed?

Yes No

If yes, please enclose a copy of the risk assessment, and the contact name and phone number  
If no, please explain why

6.7 What facilities/procedures and personnel are there for dealing with emergencies?

There are no emergencies anticipated.

6.8 Will any drugs be administered for the purposes of this study? Yes No

If yes is SCOTT approval required? Yes No

Has SCOTT approval been given? (please attach) Yes No

## 7. Expected outcomes or impacts of research

### 7.1 What is the potential significance of this project for improved health care for Maori and non Maori, and for the advancement of knowledge?

An understanding of the experience of whanau in caring for a member suffering the after effects of stroke. This understanding may lead to information that could enrich the experience of the whanau caring for the family member disabled by stroke and lead to an enhancement of the partnership between traditional and non-traditional care as experienced by the whanau.

### 7.2 What steps will be taken to disseminate the research results?

Regional hui to disseminate the results to the participants and to Te Whare Punanga Korero, and Tui Ora Ltd staff will be held in North Taranaki.

Regional hui to disseminate the results to participants and to Ngati Ruanui Tahua Iwi Authority will be held in South Taranaki.

With Tui Ora Ltd and Ngati Ruanui Tahua Iwi Authority approval, results will be submitted to relevant journals – nationally and internationally.  
Presentation at appropriate conferences.

Debriefing with local Assessment, Treatment, and Rehabilitation Services, Access Ability services, and Taranaki Health Psychogeriatric Service, following the study.

Completion of a thesis for a Masters degree.

## PART IV: BUDGET AND USE OF RESOURCES

### 8. Budget

8.1 How will the project be funded?

Personal funding with applications for some funding made to:  
Western Institute of Technology at Taranaki Research Committee, (\$1000 received).  
College of Nurses of Aotearoa, (\$750 received).  
Massey University Masterate Scholarship application made. (Declined).

8.2 Does the researcher, the host department or the host institution, have any financial interest in the outcome of this research? Please give details.

NO

8.3 Will the researcher personally receive payment according to the number of participants recruited, or a lump sum payment, or any other benefit to conduct the study? If so, please specify:

NO

8.4 What other research studies is the lead investigator currently involved with?

NONE

### 9. Resource Implications

9.1 Does the study involve the use of healthcare resources?

Yes

No

If yes, please specify:

N/A

9.2 What effect will this use of resources have on waiting list times for patients ie., for diagnostic tests or for standard treatments?

N/A

### 10. Financial Costs and Payments to Participants

10.1 Will there be any financial cost to the participant? Give examples including travel.

NO. The researcher will bear all costs associated with koha and kai.

10.2 Will the study drug/treatment continue to be available to the participant after the study ends?  Yes  No  N/a  
 If yes, will there be a cost, and how will this be met?

10.3 Will any payments be made to participants or will they gain materially in other ways from participating in this project?  Yes  No  
 If yes, please supply details

**11. Compensation for Harm Suffered by Participants**

—Is this a clinical trial under accident compensation legislation? (see form guidelines)  Yes  No

If yes, please answer the following:

11.1 Is the trial being carried out principally for the benefit of a manufacturer or distributor of the drug or item in respect of which the trial is taking place?  Yes  No

(a) If the answer to 11.1 is yes, please complete **Statutory Declaration Form B** and answer questions 11.2, 11.3 and 11.4

(b) If the answer to 11.1 is no please complete **Statutory Declaration Form A**

11.2 What type of injury/adverse consequence resulting from participation in the trial has the manufacturer or distributor undertaken to cover? (please tick the appropriate box/es)

	Yes	No
a) any injury (mental or physical)	<input type="checkbox"/>	<input type="checkbox"/>
b) only serious or disabling injuries.	<input type="checkbox"/>	<input type="checkbox"/>
c) only physical injuries	<input type="checkbox"/>	<input type="checkbox"/>
d) only physical injuries resulting from the trial drug or item, but not from any other aspect of the trial	<input type="checkbox"/>	<input type="checkbox"/>
e) physical and mental injury resulting from the trial drug or item, but not from any other aspect of the trial.	<input type="checkbox"/>	<input type="checkbox"/>
f) any other qualification (explain) <input style="width: 300px; height: 15px;" type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>

11.3 What type of compensation has the manufacturer or distributor agreed to pay?

	Yes	No
a) medical expenses	<input type="checkbox"/>	<input type="checkbox"/>
b) pain and suffering	<input type="checkbox"/>	<input type="checkbox"/>
c) loss of earnings	<input type="checkbox"/>	<input type="checkbox"/>
d) loss of earning capacity	<input type="checkbox"/>	<input type="checkbox"/>
e) loss of potential earnings	<input type="checkbox"/>	<input type="checkbox"/>
f) any other financial loss or expenses	<input type="checkbox"/>	<input type="checkbox"/>
g) funeral costs	<input type="checkbox"/>	<input type="checkbox"/>
h) dependants' allowances	<input type="checkbox"/>	<input type="checkbox"/>

11.4 Exclusion clauses:

	Yes	No
a) Has the manufacturer or distributor limited or excluded liability if the injury is attributable to the negligence of someone other than the manufacturer or distributor? (such as negligence by the investigator, research staff, the hospital or institution, or the participant).	<input type="checkbox"/>	<input type="checkbox"/>
b) Has the manufacturer or distributor limited or excluded liability if the injury resulted from a deviation from the study protocol by someone other than the manufacturer or distributor?	<input type="checkbox"/>	<input type="checkbox"/>
c) Is company liability limited in any other way?	<input type="checkbox"/>	<input type="checkbox"/>

If yes, please specify

**12. Information and Consent**

Consent should be obtained in writing, unless there are good reasons to the contrary. If consent is not to be obtained in writing the justification should be given and the circumstances under which consent is obtained should be recorded. Attach a copy of the information sheet and consent form.

12.1	By whom, and how, will the project be explained to potential participants?	Tui Ora Ltd and Ngati Ruanui Health Centre Community Health workers and principal researcher
12.2	When and where will the explanation be given?	At a hui at an appropriate venue and by use of the explanation sheet
12.3	Will a competent interpreter be available, if required?	Yes
12.4	How much time will be allowed for the potential participant to decide about taking part?	As long as they require
12.5	Will the participants be capable of giving consent themselves? - if not, to whom will the project be explained and who will give consent?	Yes by whanau members. Actual whanau member who has stroke may have speech problems however immediate family will be used to elicit understanding and consent to participation in study
12.6	In what form (written, or oral) will consent be obtained? If oral consent only, state reasons.	Written. However oral consent may be deemed sufficient and appropriate with some members of the whanau. Guidance on this matter will be from the community health worker and/or kuia and kaumatua.
12.7	Are participants in clinical trials to be provided with a card confirming their participation, medication and contact phone number of the principal investigator?	<input type="checkbox"/> Yes <input type="checkbox"/> No N/A

**13. Confidentiality and Use of Results**

13.1	How will data including audio and videotapes, be handled and stored to safeguard confidentiality (both during and after completion of the research project)?	During the study: a) secured in the offices of the Dept of Nursing and Science, WITT. b) original transcript and audiotape in the offices of Tui Ora Ltd. After the study with Tui Ora Ltd and Ngati Ruanui Tahua Iwi Authority.
13.2	What will be done with the raw data when the study is finished?	Vested with Bev Gibson, Tui Ora Ltd, Selwyn Carr, Ngati Ruanui, for safekeeping and decision regarding any further access to the data.
13.3	How long will the data from the study be kept and who will be responsible for its safekeeping?	Tui Ora and Ngati Ruanui to determine. (Usually 10 years).
13.4	Who will have access to the raw data and/or clinical records during, or after, the study?	Tui Ora and Ngati Ruanui to determine.
13.5	Describe any arrangements to make results available to participants, including whether they will be offered their audiotapes or videos.	A hui of all participants will be held to disseminate the results of the study at its conclusion to these persons. It is not intended to offer audiotapes to participants; these are to be vested with Bev Gibson, Tui Ora Ltd with a second copy held by Selwyn Carr, Ngati Ruanui. It is not intended to video any interview.
13.6	If recordings are made, will participants be offered the opportunity to edit the transcripts of the recordings?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
13.7	Is it intended to inform the participant's GP of individual results of the investigations, and their participation, if the participant consents?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
If no, outline the reasons		Information unlikely to be relevant to GP

13.8 Will any restriction be placed on publication of results?  Yes  No

If yes, please supply details

Nil by researcher – Tui Ora and Ngati Ruanui to determine any restriction – including that of the researcher -- who will be required to gain approval from Tui Ora and Ngati Ruanui prior to any publication.

#### 14. Treaty of Waitangi

14.1 Have you read the HRC booklet, "Guidelines for Researchers on Health Research involving Maori"?

Yes  No

14.2 Does the proposed research project impact on Maori people in any way?

Yes  No

14.3 Explain how the intended research process is consistent with the provisions of the Treaty of Waitangi

With the principles of Partnership, Participation and Protection kept to the fore this project sees the researcher entering into partnership with the local Taranaki Maori Development Organisation, Tui Ora Ltd, Te Whare Punanga Korero, the Taranaki Iwi health forum of which seven of the eight Taranaki Iwi are represented; and South Taranaki Iwi, Ngati Ruanui, to seek to understand the experience of the whanau coping with a member affected by stroke.

Feedback to the local District Health Board AT & R Services, Access Ability, and the Taranaki Health Psychogeriatric Service, will also further the partnership process with local Maori.

14.4 Identify the group(s) with whom consultation has taken place, and attach evidence of their support

Tui Ora Ltd – letter has been forwarded direct to you.

Arrangements have been made to meet with Te Whare Punanga Korero at their monthly meeting on April 29, 2002.

A meeting with the local AT & R Service consultant physician, Dr Lorraine Taylor, is to be held on May 1, 2002, to inform this service of the study and to keep them informed of the progress and results at the study conclusion.

Korero was held with Ngati Ruanui Tahua Iwi Authority Maori Health Committee on August 13, 2002 and agreement reached on partnership and participation between the Iwi and the researcher.

14.5 Describe the consultation process that has been undertaken **prior** to the project's development

Discussion and korero with respected Maori Health advisor and Kuia of Taranaki Iwi, Makere Wano.

Korero with staff of Tui Ora Ltd, principally Bev Gibson.

14.6 Describe any ongoing involvement the group consulted has in the project

Continued oversight of the study with all results vested into the care of Bev Gibson, Tui Ora Ltd.

14.7 Describe how information will be disseminated to participants and the group consulted at the end of the project

By hui at end of study attended by whanau participants, Tui Ora Ltd, local North Taranaki Iwi, and researcher in North Taranaki.

By hui at the end of the study attended by whanau participants, and Ngati Ruanui Tahua Iwi Authority, in South Taranaki.

A separate debriefing will be held with the AT & R Service of Taranaki Health, the Psychogeriatric Service of Taranaki Health, and Access Ability.

The Stroke Foundation of New Zealand will be forwarded a copy of the completed research study report.

15. Other Issues

15.1 Are there any aspects of the research which might raise specific cultural issues?  Yes  No

If yes, please explain

There could be concerns over the cultural safety of a pakeha undertaking research on Maori. Following the HRC "Guidelines for Researchers on Health Research Involving Maori" an in depth consultative process with local Iwi and staff of Tui Ora will be held to overcome any perceived or identified problems.

There will be liaison with the local AT & R service, principally by feedback at the end of the study.

Korero with Ngati Ruanui revealed a concern of a lack of report back following involvement of the Iwi in studies in the past. A firm commitment has been given by the researcher that full and comprehensive report back will be given at the completion of the study prior to submission of the completed thesis.

15.1.1 What ethnic or cultural group(s) does your research involve?

North Taranaki and South Taranaki Iwi Maori

Describe what consultation has taken place with the group prior to the project's development

Informal discussions in December 2001 with Bev Gibson, Tui Ora Ltd, and Makere Wano, Kuia and Maori Health Advisor.

Formal korero planned for late January did not occur due to whanau commitments of one of the participants.

Korero with Bev Gibson, Mental Health Facilitator, Tui Ora Ltd, March 4, 2002, gained agreement and support for the proposed research programme.

15.1.2 Identify the group(s) with whom consultation has taken place and attach evidence of their support

Tui Ora Ltd  
*Letter of support forwarded direct to you by them.*

15.1.3 Describe any ongoing involvement the group consulted has in the project

The researcher undertakes to give regular reports to Tui Ora Ltd as requested by them, on the progress of the study.

Assistance in verification of identified themes as the data is analysed.

15.1.4 Describe how you intend to disseminate information to participants and the group consulted at the end of the project

Hui of all participants and those involved

**16. Ethical Issues**

16.1 Describe and discuss any ethical issues arising from this project, other than those already dealt with in your answers?

NIL

Thank you for your assistance in helping us assess your project fully

Please now complete:

- the declarations (Part V)
- a drug administration form (if applicable)
- an Accident Compensation Form A or B relating to accident compensation

## Study Information Sheet

## STUDY INFORMATION SHEET

**Principal Investigator:** Andrea Michael Corbett  
Course Co-Ordinator  
Department of Nursing and Science



**Supervision:** The work of the Principal Investigator is to be supervised by:  
Professor Julie Boddy and Maureen Holdaway of Massey University.  
They may be contacted at Massey University, School of Health Sciences, Palmerston  
North  
Telephone 06 350 5799 extension 2541.

Bev Gibson, Tui Ora Ltd



Makere Wano, Te Rau Pani



**Title of Study:** Stroke Rehabilitation in Maori

**Introduction:** You are invited to take part in a study that seeks to understand the whanau experience of stroke.

You may take as long as necessary to consider whether to participate and any questions you may have may be directed to Andrea Corbett, Principal Researcher; Bev Gibson of Tui Ora Ltd; or Makere Wano, Kuia. You may decline the opportunity to participate in the study.

**About the Study:** The whanau will be gathered together at a venue of their choice and invited to relate their experience/s in having a family member affected by stroke living at home. It is known that few Maori access established rehabilitation services following stroke. This study is aimed at understanding the experience of the whanau in caring for the family member affected by stroke. It is hoped that it may yield useful information which, in time, will assist the whanau with caring for their loved one.

A minimum of six whanau groupings who have a loved one affected by stroke, will be approached by staff of Tui Ora Ltd, or Makere Wano, Kuia, to ask them to participate in the study. These whanau will be identified from knowledge of their involvement with health service providers in North Taranaki such as Tui Ora Ltd, Te Rau Pani, Piki Te Ora Ltd, the Rehabilitation services of Taranaki Health, and similar groupings.

It is planned that the study will take place in a neutral venue such as the Rangiatea campus of the Maori Studies Department of the Tech, the Kopa Manaaki room at the Bell Street campus of the Tech, at an appropriate marae, or at your own home if you prefer. It is envisaged that the discussion of the whanau experiences will take between two and three hours. The discussion will be facilitated by a community health worker from Tui Ora Ltd or Makere Wano with the Principal Researcher in attendance to observe and record the discussion.



Semi-structured interviews will be held with key informant whanau members to enable them to reflect and expand on their experiences following the whanau gathering. This person will probably be the lead caregiver of the whanau member affected by stroke. This interview will be recorded with the participant's permission and transcribed. The transcript of any such interview will be given to the participant to review and edit if changes are needed.

Following the end of the study all the observational notes, audiotapes and transcripts, and collation of data will be vested in Tui Ora Ltd for safekeeping.

**Benefits, Risks, and Safety:** It is the aim of the study that an understanding of the Maori experience of caring for a whanau member with stroke will be gained. This understanding may result in the ability to enrich the experience of the whanau caring for a member with stroke and may lead to the enhancement of the partnership between traditional and non traditional care as experienced by the whanau.

There will be no cost to the whanau for taking part in the study. Likewise there will be no payment for participation.

The Principal researcher will be responsible for all koha and kai during the course of the meetings and discussion in the course of the study.

There is no risk or safety issue involved in taking part in the study.

**Participation:** Your participation is entirely voluntary (your choice). You do not have to take part in this study.

If you do agree to take part you may withdraw at any time without having to give a reason for that withdrawal.

**General:** At the end of the study all information collected will be vested with Bev Gibson, Tui Ora Ltd, for safe keeping.

A hui will be held that will involve all participants, staff of Tui Ora Ltd, Taranaki Iwi and the Principal Researcher to enable a report to be given of the findings of the study.

During the semi structured interview process with the key informant that person will have the right to stop the interview at any time, and they do not have to answer all the questions.

**Confidentiality:** No material which could identify you will be used in any report or presentation on this study.

All written and audio taped material will be vested in Tui Ora Ltd for permanent safe keeping at the end of the study and will only be accessed on application to them.

**Results:** It is intended to publicise the results of the study. This will be done by the submission of Reports to reputable Nursing and Medical Journals, and at appropriate Conferences. Any such journal article and/or conference presentation will first be submitted to Tui Ora Ltd for approval before such publication.

**Statement of Approval:** This project has been reviewed and approved by the Taranaki Regional Ethics Committee.

The project has also been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/58. If you have any concerns about the conduct of this research, please contact Professor Sylvia V. Rumball, Chair, Massey University Human Ethics Committee, Palmerston North; telephone 06 350 5249; email: S.V.Rumball@massey.ac.nz.

**Please feel free to contact the researcher if you have any questions about the study.**

## Appendix Four

### Consent Form – Te Reo



COLLEGE OF HUMANITIES & SOCIAL SCIENCES

#### Consent Form He Tohu Whakaae

School of Health Sciences

Private Bag 11 222,

Palmerston North,

New Zealand

Telephone: 64 6 356 9099

Facsimile: 64 6 350 5668

I have read and understood the information on the Study Information Sheet.

**Kua oti i a au te panui, a, kua marama ki nga korero o tenei Rangahau Wakamarama.**

I have had the opportunity to discuss this study.

**Kua whai wa ahau ki te whiriwhiri korero mo tenei rangahau.**

I have had time to consider whether to take part.

**Kua ata whakaaro mehemea ka mahi au i te rangahau nei, kaore ranei.**

I understand that taking part in this study is voluntary (my choice) and that I may withdraw at any time.

**Kua mohio rawa ahau, kei ahau te tikanga mo tenei rangahau, a nei ka hiahia te puta atu, ka taea.**

I understand that my participation in this study is confidential and that no material which could identify me will be used in reports of the study.

**E marama ana ahau, ko aku korero ki roto i te rangahau, he mea rahui.**

I consent to any discussion or interview being audio taped and transcribed. I have been informed that I will have the opportunity to review the transcripts and make any changes that I may wish to make.

**Ka whakaaengia kia hopu aku korero, a ripene, a tuhituhi hoki. Ka taea hoki e au te whakarerekengia mehemea kaore i te whakaaetia.**

I have been informed that any such tapes and transcripts will be vested for the safekeeping with Bev Gibson of Tui Ora Ltd at the end of the study.

**Kua whakamohio mai, ma Bev Gibson o Tui Ora nga hopunga korero e mau mai i te mutunga o tenei rangahau.**

I understand that a hui will be held for the outcomes of the study to be shared with me and my whanau.

**E marama ana ahau, kei te tu tetehi hui kia puta atu nga korero o tenei rangahau.**

I ..... hereby give consent to take part in the study.

**Ko ahau ko ..... e whakaae ana ki tenei rangahau.**

Date

Ra .....

Signature of witness

Ingoa tohu o te kaitautoko .....

Signature

Ingoa .....

Name of witness

Ingoa a te kaitautoko .....

Full name of researcher

**Ko te ingoa katoa o te Kaitangahau: Andrea Michael Corbett**

Study explained by

**Ma ..... tenei rangahau e whakamarama**

Signature

Ingoa .....

Date

Ra .....



# CONSENT FORM

I have read and understood the information on the Study Information Sheet.

I have had the opportunity to discuss this study.

I am satisfied with the answers I have been given.

I have had time to consider whether to take part.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw at any time.

I understand that my participation in this study is confidential and that no material which could identify me will be used in reports on this study.

I consent to any discussion or interview being audio taped and transcribed. I have been informed that I will have the opportunity to review the transcripts and make any changes I may wish to make.

I have been informed that any such tapes and transcripts will be vested for safekeeping with Bev Gibson of Tui Ora Ltd at the end of the study.

I understand that a hui will be held for the outcomes of the study to be shared with me and my whanau.

I.....hereby give consent to take part in this study.

Date:.....Signature of witness:.....

Signature:.....Name of witness:.....

Full name of researcher:.....

Study explained by:.....

Signature:.....

Date:.....



Massey Human Ethics Committee Approval – June 6, 2002

**Boddy, Julie**

---

**From:** Kahukoti, Karen  
**Sent:** Thursday, June 6, 2002 9:56  
**To:** [REDACTED]  
**Cc:** Boddy, Julie; Holdaway, Maureen  
**Subject:** HEC: PN Protocol 02/58 - Outcome

**02/58      Stroke rehabilitation in Maori**  
Ms Andrea Corbett (HEC: PN Protocol 02/58)  
Department: Health Sciences - TURITEA  
Supervisor(s): Dr Julie Boddy, Mrs Maureen Holdaway

Thank you for the above protocol that was received and considered by the Massey University Regional Human Ethics Committee: Palmerston North at their meeting held on Thursday 23 May 2002.

The protocol was approved, subject to approval by Professor Sylvia V Rumball (Chair) of the reply to the following questions and comments:

- clarify who will be transcribing, if not the Researcher supply a copy of a Transcriber's Agreement,

Consent Form

- ensure that Consent Form is printed on Massey University departmental letterhead,
- indicate that tapes and transcripts will be stored up to 10 years under storage policy of Tui Ora Ltd,
- supply a copy of the amended Consent Form,

Information Sheet

- amend statement to read "This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/58. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Regional Human Ethics Committee: Palmerston North, telephone 06 350 5249, email S.V.Rumball@massey.ac.nz.", note that protocol number is incorrect,
- supply a copy of the amended Information Sheet.

Please supply to Miss Karen A Kahukoti (Secretary), one (1) copy of your reply.

Any departure from the approved protocol will require the researcher to return this project to the Massey University Human Ethics Committee for further consideration and approval.

Yours sincerely

Professor Sylvia V Rumball, Chair  
**Massey University Regional Human Ethics Committee: Palmerston North**

Miss Karen A Kahukoti  
Ethics Administrator

**Massey University Human Ethics Committee Approval – June 27, 2002**

Professor Sylvia V Rumball  
Telephone: 64 6 350 5249 Telephone: 64 6 350 5573  
Email: S.V.Rumball@massey.ac.nz Email: K.A.Kahukoti@massey.ac.nz

**Massey University**

Private Bag 11 222,  
Palmerston North,  
New Zealand  
Telephone: 64 6 356 9099

27 June 2002

Ms Andrea Corbett  
PG Student  
Health Sciences  
**TURITEA PN351**

Dear Andrea

**Re: HEC: PN Protocol – 02/58  
Stroke rehabilitation in Maori**

Thank you for your correspondence and the amended protocol.

The amendments you have made now meet the requirements of the Massey University Human Ethics Committee and the ethics of your protocol are approved.

Any departure from the approved protocol will require the researcher to return this project to the Massey University Regional Human Ethics Committee: Palmerston North for further consideration and approval.

A reminder to include the following statement on all public documents "This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/58. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Regional Human Ethics Committee: Palmerston North, telephone 06 350 5249, email S.V.Rumball@massey.ac.nz."

Yours sincerely



Professor Sylvia V Rumball, Chair  
**Massey University Regional Human Ethics Committee: Palmerston North**

cc Dr Julie Boddy  
Mrs Maureen Holdaway  
Health Sciences  
TURITEA PN351

2 May 2002

Andrea M Corbett



Dear Andrea

**Stroke rehabilitation in Maori: A qualitative study into the experiences of whanau caring for a member who is disabled by the effects of a stroke.**

**Investigator:** Andrea Michael Corbett

**Ethics Reference:** 02/03/005 Taranaki

At our sub-committee meeting held 1 May 2002 your above described application was approved, subject to receipt of the amendments we discussed at our meeting with you on 1 May 2002. You advised that an amended version was "in the mail" to this Committee.

Please note that under the Committee's approval you are obligated to advise the Committee if this application does not go ahead, changes in any way, is terminated before completion date or is completed early.

You are also obliged to complete a Progress Report at 12 months and a Final Report at the completion of the study. For this purpose, a Report Form is enclosed. When research involves Maori, a copy of your report is also to be sent to the Maori Research Units (list attached).

We wish you all the best with the study and look forward to receipt of your report in due course.

Yours sincerely

A handwritten signature in blue ink that reads "Catherine Quin".

Catherine Quin  
**CHAIR**

*a he iti, He pounamu koe*

1 May 2002

Kia ora,

This is to inform you that Andrea has commenced her consultation process with Te Whare Punanga Korero, the Iwi health forum of Taranaki. Arrangements have been made for her to present at our scheduled monthly hui on the 20<sup>th</sup> May 2002.

As deadlines and timing is critical for Andrea to submit her application to Massey, discussion has been held with some members of the Board who recognised that Andrea has in place, supervision by two Maori health professionals, one of whom is acting in the role of kuia as well as that of facilitator.

It was also acknowledged that it is her intention the final report will be presented and offered back to the participants and that all data was to be held and secured by Tui Ora Limited, a Maori Development Organisation.

Te Whare Punanga Korero do not wish to delay this process and would like Andrea to proceed in her research as the final result is also of interest to us.

We wish her well and look forward to her presentation on the 20<sup>th</sup> May 2002.

Heoi ano na



Pat Bodger  
Secretary  
Te Whare Punanga Korero

Tui Ora Ltd Letter of Support – March 25, 2002

COPY



TUI ORA LTD

"Let Unity Prevail"

PO Box 8119 New Plymouth  
New Zealand

Phone: 06 759 4064

Fax: 06 759 1799

25 March 2002

Dr J Boddy,  
Professor of Nursing,  
School of Health Sciences,  
Massey University

Re: Letter of Support for Research Proposal

Tena Koe Dr J Boddy,

E nga iwi, e nga reo, e nga karangatanga maha o nga hau e wha, tenei te mihi atu ki a koe.

Andrea Corbett, Nursing Tutor, has discussed with Tui Ora Limited her proposed thesis study in 'Stroke Rehabilitation In Maori: A Descriptive Study'.

Tui Ora Limited is pleased to provide support for the duration of this project. Tui Ora Limited has also agreed to take responsibility for the welfare and security of information and any documentation gathered from this study.

We wish Andrea best wishes for her proposed research and look forward to the outcome of her investigations. Further enquiries can be obtained from the under-signed writer.

Noho ora mai,

A handwritten signature in black ink, appearing to read 'Bev Gibson'. The signature is fluid and cursive, with the first letters being larger and more prominent.

Bev Gibson  
Deputy Chief Executive Officer  
Tui Ora Limited.

Cc

- Andrea Corbett, Course Co-Ordinator, Department of Nursing and Science, Western Institute of Technology of Taranaki
- Catherine Quinn, Chairperson, Taranaki Ethics Committee
- Hayden Wano, CEO, Tui Ora Limited

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