



## Copyright Statement

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand). This thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognise the author's right to be identified as the author of this thesis, and due acknowledgement will be made to the author where appropriate.
- You will obtain the author's permission before publishing any material from their thesis.

To request permissions please use the Feedback form on our webpage.  
<http://researchspace.auckland.ac.nz/feedback>

## General copyright and disclaimer

In addition to the above conditions, authors give their consent for the digital copy of their work to be used subject to the conditions specified on the Library [Thesis Consent Form](#)

**Recognising Women's Responses to Heart Disease  
Symptoms: Different Groups Respond in  
Different Ways**

**Cheryl Anne Campbell**

A thesis presented in fulfilment of the requirements for the degree of Doctor of  
Philosophy in Social and Community Health at the School of Population Health,  
Faculty of Medical and Health Sciences, University of Auckland,  
Auckland, New Zealand, 2004

## **ABSTRACT**

### **Recognising Women's Responses to Heart Disease Symptoms: Different Groups Respond in Different Ways**

This study explored the recognition and understanding of angina or heart attack symptoms and the reasons for delay in seeking appropriate care with particular reference to women and Maori. The study population consisted of European and Maori people aged between 45 and 85 years either diagnosed as being at high risk of having a heart attack, experiencing angina, or requiring admission to hospital with their first heart attack. The study methodology is a qualitative analysis of 30 individual interviews (nine European women, nine European men, five Maori women and seven Maori men) conducted using grounded theory. A semi-structured interview schedule followed the sequence of events that led to seeking medical care. Interviews were audio taped, transcribed and coded using a computer software programme. The data analysis included collaboration with Maori.

Delay times from symptom onset to hospital admission were: five participants delayed less than two hours (range 1 hour to 1 hour 30 minutes), and six participants delayed more than 2 hours (range 2 hours 30 minutes to 10 hours). Delay times from symptom onset until attending a medical clinic were: four participants delayed less than 2 hours (range 1-2 hours) and fourteen participants delayed more than 2 hours (range 4-24 hours). Reasons for delay, common to both European and Maori were: difficulties recognising their symptoms, self treatment, obtaining reassurance, differences in symptom descriptions between the participants and doctors, and several participants' symptoms were initially misdiagnosed. In the European group specific reasons related to delay were: a lack of knowledge, and consultations with general practitioners. European women reported that uncommon symptoms were disregarded in the pre-diagnosis period. For Maori, specific reasons for delay were: a greater emphasis on consulting family and minimising the symptoms. Participants had a codified set of rules within the self-

regulatory model that determined their actions that became the emergent theme in the overarching category – ‘Recognising Women’s Responses to Heart Disease Symptoms: Different groups respond in different ways’. The fact that people have different perceptions about symptoms, endure symptoms in different ways, obtain reassurance in different ways, and take action in different ways formed the categories that made up the theoretical concept. The rules differed according to gender and culture. The study findings will contribute to the understanding of gender and cultural differences in care seeking for heart disease symptoms.

## ACKNOWLEDGEMENTS

This research would not have been possible without the support of many wonderful people. Undertaking this doctorate has been a responsibility to women, something that could not be lightly abandoned in its more difficult stages. It has been a solitary dedication, sometimes arduous and at other times steeped in the joy of discovering new things about myself and about lives of women. This work has been a team effort. So many people came into my life because of this research while others stood alongside me from the beginning. I would like to thank you all.

To the participants who shared their time, private lives and stories, I owe you all so much because you have given your experiences in order that others with heart disease might benefit. I hope that my efforts have lived up to your expectations.

To my supervisors Associate Professor John Raeburn, Professor David Thomas and Professor Colin Mantell, each experts in their fields who supported and cared about me throughout the entire process. To Associate Professor Bruce Arroll and all of the General Practitioners, and nursing staff who gave up their time and allowed me to carry out research that intersected the private domains of patient-practitioner relationships.

Special thanks to Professor Robert Beaglehole, Professor Warren Smith, Professor John Neutze, Professor Harvey White, Professor Alan Kerr, Professor Norman Sharpe and again to Associate Professor John Raeburn, each of whom never doubted that I could make this contribution to women's heart disease.

To my advisors Dr Fiona Stewart and Dr Linda Cameron for superb clinical knowledge, caring and support; Reverend Barrie MacCuish for his spiritual guidance at times when I was at a low ebb, Dr Lorna Dyall who stood by me with courage, support, and aroha as she shared her knowledge of Maori women's experiences, Iritana Hankins a true friend and colleague and Reverend Tawhiao Tioke whose storehouse of knowledge truly

amazed me. Each one encouraged and supported me when I stumbled along the rocky path of learning. To Robyn Kahukiwa, a gifted artist who allowed me to use her paintings.

To my friends Dr Diana Rabone, Paddy Hughes and Lindsay Walker as well as their children Magnus, Lachlan and Madeleine, Diane and Neil Wakefield, Liz Painter, Grace and Ronald Wong, Anne Iosefa, Sandy and Peter Simpson. I was able to share the triumphs and misgivings of my journey, or seek solace as the thesis took shape.

To Kay Acraman and Lorraine Nielsen for their friendship, love and expertise with the manuscript and databases; Pamela Andrew and Christine Payne for friendship and technical support and Mary Kisler for her expertise in art history.

Finally to my children, Blair, Caryn, Rochelle and son-in-law Christophe, special gifts in my life, and my parents Ronald and Irene Campbell for your constant love and practical support enriching my life in so many ways.

This thesis was made possible through a grant from The National Heart Foundation of New Zealand.

## DEDICATION

*This work is dedicated to Diane Margaret Wakefield who has taught me so much about women's experiences of heart disease and to Algie Edwin Moore (Uncle Tookie) who does not hesitate to call the ambulance.*

*For my great, great grandmothers Sarah Ann Bryant, Florence Snelgar and Maria Robinson, my grandmothers Olive Mary Robinson and Minnie Mary MacIntyre-Campbell, my mother Irene Maria Campbell, my aunts Violet Florence Moore, Josephine Mary Godfrey and Joan Ellenor Russ, my sister Debra Marie Campbell, my cousin Sandra Dawn Lock and my cherished daughters Caryn Marie Delarue and Rochelle Anne Bright.*

# TABLE OF CONTENTS

ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iv
DEDICATION.....	vi
TABLE OF CONTENTS.....	vii
LIST OF TABLES.....	xiv
LIST OF FIGURES.....	xv
LIST OF ABBREVIATIONS.....	xvi
PROLOGUE.....	xvii
CHAPTER I: INTRODUCTION.....	1
Overview.....	1
Preamble.....	1
Aims and objectives of the study.....	5
Objectives.....	5
Thesis Structure.....	6
Summary.....	10
CHAPTER II: LITERATURE REVIEW.....	11
WOMEN AND HEART DISEASE.....	11
Overview.....	11
Introduction.....	11
Literature Search Strategy.....	12
Background.....	12
A significant women’s issue - heart diseases and stroke.....	12
World Health Organisation mandate for women and heart disease.....	14
Why has women’s heart disease lacked attention from scientific communities?.....	15
Differences in heart disease between women and men.....	17
Differences in diagnosis and treatment for women and men.....	17
Social context of heart diseases and stroke among women.....	18
The status of women in New Zealand.....	19
Coronary heart disease in New Zealand.....	20

Symptoms of myocardial infarction, gender and ethnic differences .....	22
Perceptions of heart attack symptoms in women and Maori .....	23
Demographic and clinical predictors of delay .....	26
Previous research on psychological variables.....	28
Delay times .....	31
People’s beliefs about symptoms.....	32
Age can influence beliefs about symptoms .....	35
Previous studies of illness perceptions and myocardial infarction .....	38
Summary .....	40
CHAPTER III: LITERATURE REVIEW .....	41
THEORY DEVELOPMENT .....	41
Overview.....	41
Part One: Heart beliefs - Introduction.....	42
The influence of symbolism and imagery on beliefs about the heart .....	42
Changes in beliefs and meanings .....	47
Changing perceptions about the heart.....	49
Women’s place in philosophical and medical debates.....	50
Superstitious beliefs impeded attempts at heart surgery.....	55
How stereotypes influence medical practice.....	56
Part Two: Gender and Culture .....	57
Gender.....	58
Cultural constructions of gender .....	58
Gender stereotypes and care seeking for heart disease.....	60
Culture.....	61
Defining culture .....	61
Constructions of culture .....	61
Cultural factors influence health behaviour .....	62
Cultural influences on interpretations of health knowledge .....	63
Cultural groups can share common illness beliefs.....	64
Difficulties separating individual and cultural representations.....	66
Do cultural factors influence illness representations?.....	68

Maori health rights in terms of the Treaty of Waitangi .....	69
Defining Maori cultural identity .....	69
Summary .....	72
CHAPTER IV: GROUNDED THEORY RATIONALE .....	73
Overview.....	73
Introduction: Theoretical perspectives.....	73
Grounded theory .....	74
Feminism.....	75
Symbolic interaction, phenomenology, and marxism.....	76
Using grounded theory.....	77
Rationale for interview questions .....	77
Theory aspects of the interview process .....	78
Rationale for the interview process.....	80
Grounded theory sampling and analysis .....	82
Data analysis .....	84
Summary .....	86
CHAPTER V: METHODOLOGY .....	87
Overview.....	87
Introduction.....	87
Study design and aim .....	88
Study objectives .....	88
Ethical requirements .....	89
Sample.....	89
Sample size .....	89
Sampling methodology .....	90
Selection criteria and their justification .....	91
Consultation about recruitment of participants.....	93
Interviews with Maori key informants.....	94
Qualitative interviews .....	94
Data collection process .....	97
Data saturation .....	103

Data analysis .....	104
Theoretical decisions .....	104
Summary .....	119
CHAPTER VI: RESULTS: SYMPTOM PERCEPTIONS .....	120
Overview.....	120
Introduction.....	120
Part One: Delay times .....	121
Summary of delay times .....	122
Part Two: People perceive symptoms in different ways.....	124
Summary of symptom descriptions.....	133
Summary .....	136
Part Three: People have different expectations about symptoms .....	136
Summary .....	142
Discussion.....	143
Delay times .....	143
Rules governing relationships.....	143
European women’s difficulties in recognising heart disease symptoms .....	144
European men’s difficulties in recognising symptoms .....	146
Maori symptoms .....	146
Maori women’s difficulties in recognising heart disease symptoms .....	146
Summary .....	150
CHAPTER VII: RESULTS - MAORI DIMENSION .....	151
Overview.....	151
Introduction.....	151
Part One: Maori beliefs about the heart: Informant data .....	152
The symbolism of the heart for Maori women .....	153
Summary of beliefs about the heart .....	156
Part Two: Traditional health treatments .....	156
Traditional treatment for chest pain .....	157
Modern Maori responses to bodily symptoms and chest pain .....	158
Summary of chest pain.....	159

Part Three: Influences on care seeking .....	159
Maori women seeking contemporary health care .....	159
Poverty influences care seeking.....	160
Whanau influences care seeking .....	160
Doctors' communication influences Maori care seeking.....	161
Summary of care seeking.....	162
Discussion.....	163
Maori perspectives on care seeking .....	163
Maori beliefs about the heart .....	164
Poverty affects Maori care seeking.....	165
Summary .....	165
CHAPTER VIII: RESULTS - ENDURING SYMPTOMS.....	167
Overview.....	167
Introduction.....	167
Part One: Symptoms .....	167
Summary .....	175
Part Two: Discussion of enduring symptoms .....	176
Coping in wise women's ways .....	176
Caring about others .....	180
Summary .....	182
CHAPTER IX: RESULTS.....	184
REASSURANCE FOR SYMPTOMS .....	184
Overview.....	184
Part One: People obtain reassurance in different ways.....	184
Introduction.....	184
Summary .....	197
Part Two: People take action in different ways .....	198
Participant data - People take action in different ways.....	198
Summary .....	202
Summary of key findings.....	203
Discussion.....	210

Obtaining reassurance .....	210
Self treatment .....	213
Communication with doctors .....	213
Participant's perceptions about consulting a doctor .....	215
Age influences visits to the doctor .....	215
Patient centred interactions with doctors .....	216
Summary .....	217
<b>CHAPTER X: IMPLICATIONS .....</b>	<b>219</b>
Overview .....	219
Introduction .....	219
Recognising women's risk for heart disease .....	221
Symptom interpretations .....	222
Self-regulatory model .....	223
Recognising women's symptoms .....	225
Recognising women's unique coping strategies for painful symptoms.....	226
Doctors need to recognise women's heart symptoms.....	227
Recognising confusion about heart symptoms .....	228
Participants' expectations about symptoms .....	230
Beliefs drive coping strategies .....	230
Confusion about heart attack images .....	231
Confusing contemporary health threats .....	233
Public perceptions of emergency services .....	234
Recognising Maori perspectives .....	235
New approaches to education programmes .....	236
Strengths and limitations of the study.....	236
Conclusion .....	238
Recommendations.....	239
Prevention and management strategies for women and heart disease .....	239
Recognising women's risk for heart disease.....	240
Recognising women's symptoms of acute coronary syndrome or AMI.....	242
Recognising confusion about heart attack symptoms .....	243

APPENDIX A: Hospital Study Interview Schedule.....	245
APPENDIX B: Community Study Interview Schedule.....	251
APPENDIX C: Hospital Study Invitation.....	257
APPENDIX D: Community Study Invitation.....	261
APPENDIX E: Hospital Study Consent Form.....	265
APPENDIX F: Community Study Consent Form .....	268
APPENDIX G: Maori Invitation .....	271
APPENDIX H: Maori Consent Form .....	275
APPENDIX I: Lists Of Themes From Qualitative Studies .....	277
APPENDIX K: Profile Of Participants.....	279
APPENDIX L: Data Collection Process And Charts .....	281
APPENDIX M: Preferences For Survival Data Chart.....	285
LIST OF REFERENCES .....	286
GLOSSARY OF MAORI TERMS.....	309

## LIST OF TABLES

Table 2.1	Deaths (in 000s) due to cardiovascular disease (CVD) and to infectious and parasitic disease (IPD) in 30-69 year olds by sex and region, 1990	14
Table 2.2	Reported affect of symptom recognition, medical consultation and self-treatment on pre-hospital delay	26
Table 2.3	Reported affect of socio-demographic variables on pre-hospital delay times	27
Table 2.4	Statistically significant studies, numbers of patients, and pre-hospital delay times	32
Table 2.5	Attributes of the self-regulatory model	33
Table 5.1	Sample of participants	90
Table 6.1	Delay times for participants admitted to hospital for a first acute myocardial infarction	123
Table 6.2	Delay times for participants in the community	124
Table 9.1	Differences in symptom descriptions between doctors and European participants	193
Table 9.2	Differences in symptom descriptions between doctors and Maori participants	194

## LIST OF FIGURES

Figure 3.1	This painting is called Nero supervises the dissection of his mother Agrippina. It depicts a King with his gold crown symbolising political power as well as control over the woman's death and subsequent defilement of her body	45
Figure 3.2	Symbolic use of the heart shape	45
Figure 3.3	The Medieval Medical Miniature is called the Disease Woman, is depicting the heart in the correct place and the uterus is located near the hip instead of in the centre of the pelvic area	53
Figure 3.4	A Miniature from a fourteenth-century "Historie Ancienne." A female surgeon performing a caesarean section to deliver a baby	54
Figure 5.1	Analytical memo box	110
Figure 5.2	List of independent categories	111
Figure 6.1	A painting by Robyn Kahukiwa called Hine-titama, daughter of Tane and Hine-ahu-one a fusion of godly and earthly elements	147
Figure 7.1	This painting called E Hine, Ko Koe Te Whare Tangata by Maori artist Robyn Kahukiwa depicts the symbolic place of the heart.	154
Figure 8.1	This painting called Kia U by Robyn Kahukiwa depicts the links between hearts, breasts and the womb	180
Figure 9.1	Model of response to heart disease symptoms	207
Figure 9.2	Self-regulatory components of the symptom model	208

## LIST OF ABBREVIATIONS

<b>AMI</b>	Acute Myocardial Infarction
<b>ARCOS</b>	Auckland Regional Coronary and Stroke Study
<b>CCU</b>	Coronary Care Unit
<b>CHD</b>	Coronary Heart Disease
<b>CPR</b>	Cardiopulmonary Resuscitation
<b>CVD</b>	Cardiovascular Disease
<b>ECG</b>	Electrocardiogram
<b>GP</b>	General Practitioner
<b>GUSTO</b>	Global Utilisation of Streptokinase and Tissue Plasminogen Activator for Occluded Arteries
<b>IHD</b>	Ischaemic Heart Disease
<b>S-T EMI</b>	The portion of the segment between the end of the S wave and the beginning of the T wave on the electrocardiogram, Elevation Myocardial Infarction
<b>WHO</b>	World Health Organisation

## PROLOGUE

On the morning of the last day of the First International Year for Women in December 1975, my second daughter was born. It had been a difficult pregnancy and her arrival had been long awaited. As I gazed at her beautiful auburn hair, her rosy cheeks and her lovely eyes I knew that she would be a force for goodness in this world. I saw that she would go far as indeed she has. What I did not know was that she was physically a little imperfect. She was admitted to the children's ward at Green Lane hospital, Auckland, a few months after her birth. She was diagnosed with an arterial stricture in her left pulmonary artery and had a hypoplastic left lung as a result of the restricted blood flow to that part of her body.

For weeks she had to undergo painful tests, which tore at my very physical being. If only I could take the pain for her. My nights were restless, my breasts aching for my baby who had to remain in the ward without me. My secret fear, that she would stop breathing and die lives with me still. Medical staff debated the removal of the lung and some doctors considered that it might be cancerous. It was the 70's and mothers were discouraged from staying on the ward, and in my case visits to the ward were restricted to afternoons because I had no transport other than the offer of rides with friends when it suited their schedules. I had to stay with friends, as my home was located in Northland. Furthermore, I had two toddlers who needed their mother's attention - one dark-eyed adopted son and my first born, a daughter with pale blonde hair. These two preschool siblings, each with their own unique way of doing things, were anxious about their missing baby sister

Six weeks later my youngest daughter was discharged with a dairy-free diet and a reprieve from the possibility of surgical removal of the left lung. For many weeks she suffered with asthma and pneumonia, giving me little sleep. I became exhausted emotionally and physically. I collapsed and both children were farmed-out to strangers while I recovered. It was the 1970's before community support systems were in vogue and church volunteers provided assistance, in the days when attitudes such as a perfectly

tidy house equated with a happy, successful life. To accept community assistance I had to endure the disapproval of family and friends. Their perception was that I had failed as a mother. The only thing that kept me going was the woman general practitioner who provided practical, community help and support - a rare thing in those days.

My collapse was the impetus to rise above the worst thing a mother could experience – the possibility of the death of a baby that you nurse at your breast whilst still smiling at her. My baby daughter grew and thrived through nurturing, a good diet and active participation in physical activities.

Life seemed to come full circle for me after I had raised the children to school age. I took up study as a counsellor, social worker and psychotherapist. I returned to hospital as a health professional fully aware of how people suffered when loved ones are having a health crisis. Several years into my chosen career I applied to work at Green Lane Hospital.

I was accepted and allocated the Paediatric Cardiology Children's ward. It was strange to meet the doctors who had favoured a non-surgical intervention for my baby – radical treatment in the 70's where cutting things was a common cure for many ailments. How was it for me? How did I feel about the memories of my sick baby? Well, it proved to be the blossoming of a fulfilling vocation. I loved working at Green Lane where, as staff, you are part of a caring culture that helped children, adults and their extended families. Each day I felt the mystery of life and death, the sadness, loss and tears, and the joys of healing.

As my time at Green Lane progressed I worked on my first research project with people who had heart rhythm disturbances. I had been given the opportunity to work, research and learn about heart disease and its treatment across many cardiac specialities. Senior Cardiologists encouraged me to present my research at their regular seminars. They motivated me to continue my academic study and research. As a result of their support I

was seconded to The National Heart Foundation and helped establish an Auckland Regional Cardiac Rehabilitation service.

During the late 90's I was involved in a serious car accident. My hospital room was covered with cards from family, cardiac staff and cardiac patients. Besides wanting to recover from my injuries for my family's sake, I was eager to return to my work within the 'heart family'.

It took months of painful rehabilitation to use my knees and walk properly. After six months I started my research project for a Masters in Public Health. I had decided that life was far too short to waste and I had a strong desire to do what I loved – working with people who had heart disease. If my supervising professor had discouraged me at this point, I would have given up. He questioned me as to why I was nervous about doing the research. I responded by admitting that I may have to have one operation on my knee sometime in the academic year. Three operations later he was still there critiquing my dissertation that, despite racking pain, I finished with Honours.

Finally life has now turned full circle and it is me, rather than my daughters, experiencing concern about upholding women's causes. As I was preparing the proposal for this research, the literature unfolded a puzzle about women and heart disease. It was a bigger issue than psychological reaction to symptoms. It encompassed the physiological process of heart symptoms in a woman's body, which was turning out to be quite different from that of men. It was too big for me tackle alone. I almost gave up. Intuitively, I phoned Dr Fiona Stewart who found the Women's Ischaemia Syndrome Study (Merz et al., 1999) on the Internet. Together, over a cup of tea in her garden, we decided that my study needed to be a pilot study for Women and Heart Disease, this being the biggest killer of women, especially as more women in the workforce emulate the lives of men. What is different for women is that they have a double burden - retaining a job and filling a role as family caregiver. The circle has turned and I will continue my vocation – perhaps to help save the lives of my daughters as they embrace contemporary roles with dual responsibilities for family and the workplace.

# CHAPTER I: INTRODUCTION

*In an age of exploration one can always choose varieties of truth.*

Janet Frame, Author (Orsman & Hurley, 1992)

## **Overview**

This chapter will outline the purpose of undertaking this research and the overarching study aims. The study population will be drawn from a group of Maori and European women and men and the time addressed will be their responses to their heart attack symptoms both in a community setting and after admission to hospital. An explanation of the study purpose outlines the empirical reasons for undertaking a qualitative study. Then study aims and objectives are described with particular emphasis on women's responses to symptoms of heart disease. Finally the structure of the thesis is presented with a concluding summary.

## **Preamble**

The decision to undertake a qualitative study exploring the recognition and understanding of heart attack symptoms in women was influenced by the researcher's dissatisfaction with the findings of her previous literature review and research. (Campbell, 1998). The term qualitative research is described metaphorically (Creswell, 1998) as a fabric composed of many threads, colours and different textures. Qualitative research is not easy to explain, but there are frameworks, like looms that weave fabric, that hold qualitative research together. This methodology was chosen by the researcher to capture a myriad of social interactions surrounding the phenomenon of delays in care seeking for heart attack symptoms (Creswell, 1998).

The term 'patient delay' (Safer, Tharps, Jackson, & Leventhal, 1979) was used to describe the interval between when a sick person first noticed their symptoms to the time of their arrival at hospital. The term itself has its roots in biomedicine where the overriding philosophy is to cure or control illnesses. There has been a great deal of research on patient delay times for heart attack symptoms most of it having been conducted within the biomedical model. Interestingly, over a period of two decades

no medical solution was found for this problem and it began to be discussed as a phenomenon that medical researchers could not cure easily.

During the 80's and 90's health psychologists began to investigate patient delay within mainstream psychology (L. W. Kenyon, Ketterer, Gheorghiadu, & Goldstein, 1991; Kolitz, Antoni, & Green, 1988; Wielgosz, Nolan, Earp, Biro, & Wielgosz, 1988). Psychologists took the same positivist approach as the medical profession and used quantitative methodology to predict and control the behaviour of their research subjects. Investigations varied widely from testing personality factors (Kolitz et al., 1988) and investigating denial, to examining symptom appraisal and relief seeking for pain. A number of terms sprang up as a result of the problem-focused orientation used by medical psychological researchers. These terms showed that the blame for the problem of patient delay was placed squarely on the patients. The terms were victims, sufferers, deniers, people with coronary-prone behaviour, maladaptive behaviour, delay prone and women who were reluctant to lose control (Dempsey, Dracup, & Moser, 1995; L. W. Kenyon et al., 1991; Wielgosz et al., 1988).

Theoretical studies of people's cognitive process received little attention until the late nineties (Campbell, 1998; Dracup et al., 1995; R. Horne, James, Petrie, Weinman, & Vincent, 2000). More recently, attempts by health psychologists to solve the problem of patient delay have used the self-regulatory framework (H. Leventhal & Cameron, 1987). While the self-regulatory model is not new, it has not been used widely in the study of patient delay (H. Leventhal, Leventhal, & Cameron, 1999). The questionnaire used for the pilot study (Campbell, 1998) was based on traditional 'predict and control' quantitative methodology (H. Leventhal et al., 1999). After testing this questionnaire and comparing it to other questionnaires used in the Auckland Regional Coronary and Stroke study (Doggen, van der Palen, & Beaglehole, 1993), the researcher found that it did not capture a full picture of events leading up to the acute admission.

Moreover, the participants had revealed valuable information at the end of the questionnaire, when they were asked to answer some open-ended questions (Charmaz, 1990). It was these conversations that reminded the researcher how she had enjoyed listening to people recount their experiences of heart disease in her clinical work at

Green Lane hospital. These verbal findings reinforced the researcher's belief that investigators were still shaping the data from their own assumptions. Data was being reduced to fit within specifications whilst ignoring the social and cultural context surrounding an individual's response to their heart attack symptoms. More verbal data needed to be collected about people's experiences before embarking on larger investigations.

The researcher realised that she needed to move away from the positivist (M. Murray & Chamberlain, 1999) paradigm that assumed that empirical methods would achieve an objective view of delays in care-seeking. Researchers are not value-free and the facts or theories that evolve are always value laden. More importantly, the participants in her research study were equally involved in constructing the research data. The participants' interaction with the researcher was a vital piece of the investigative process (Charmaz, 1990; M. Murray & Chamberlain, 1999). This type of research is a construction determined by the historical, physical, and social context in which it is conducted. It is not possible for the researcher to be neutral or value-free from the phenomenon that is being investigated. This approach seeks to understand complex interpretations of the phenomenon under investigation instead of measuring variables related to a hypothesis (Creswell, 1998). Therefore, qualitative research involves understanding and interpreting the meaning of the phenomenon. It is grounded in the field data rather than establishing causation from statistically significant analysis.

The significance of language in constructing reality has been one of the central arguments in critiquing positivist paradigms. It moves forward from traditional psychological variables and changes them into constructions located in a historical and social context. Critics of the biopsychosocial model argue that the medical realm should be interpreted from a psychological, social and cultural viewpoint (M. Murray & Chamberlain, 1999).

What researchers using the qualitative approach choose to interpret from their data is inevitably influenced by their own assumptions and values. Theories (Creswell, 1998) derived from qualitative methodology can never be completely objective and will be value-laden. However, researchers can provide a commentary about their

point of view in relation to the phenomenon being researched. It can reveal how the researcher understands the world and views the data. The concept that the researcher's understanding is a construction is problematic for conducting the study within a positivist quantitative paradigm that is assumed to be value-free. Quantitative research has outcomes that are judged in terms of criteria such as reliability and validity. Such outcomes allow for replication of studies to confirm findings by peer review. Qualitative research findings are tested in a different way. The trustworthiness of the data is assessed in the following ways: by consistency, stakeholders' checks, comparisons with previous research on the same topic, or checking the usefulness of the findings for policy and service planning.

The study objectives with their emphasis on women were shaped by the changes in recent research for cardiovascular disease. New clinical initiatives were taking place. Investigators were beginning to examine more closely the differences in symptom presentation at hospital of men and women with actual symptoms of heart disease (Merz et al., 1999). New separate diagnostic protocols for women's symptoms were being tested because there was some evidence that women experience less common symptoms. Also, there was a growing literature on heart disease in women (Legato, Padus, & Slaughter, 1997; Merz et al., 1999; SoRelle, 1999; Wenger, 1997). In 2001 the First International Conference on Women, Heart Disease and Stroke was convened, some 30 years after research studies for men. The researcher was interested in the reasons as to why this situation had occurred. How had it happened that women were left so far behind? The researcher did not know the answer.

The researcher's decision to recruit a sample that included Maori was influenced by the evidence of high mortality rates and prolonged delays before reaching hospital (Bullen, 1997). The researcher's rationale was that the study was meaningless unless it included exploration of a population at the highest risk of death from heart disease. The Maori consultation and collaboration process that ensued is discussed in the Chapter Five - Methodology. The researcher received support from colleagues in the Section of Maori Health, University of Auckland who considered it vital to include Maori in the pilot study.

A lot of new ground had to be covered when approaching a study of women and Maori heart disease symptoms. It was important to obtain field data without making assumptions as to what it would reveal. Therefore, the researcher chose the qualitative approach of grounded theory to meet this requirement, with the aim being to collect data to learn more about the symptom descriptions for both women and men, Maori and European, as well as delays in care-seeking for heart attack symptoms.

### **Aims and objectives of the study**

This study aims to explore the recognition and understanding of angina and heart attack symptoms and the reasons for delay in seeking appropriate care with particular reference to European and Maori women. The intention is to develop a questionnaire to investigate care-seeking for heart disease symptoms. It is hoped that the methodology developed during this research will be of use for future researchers in the area. The study findings will be used to make recommendations for a community education programme. Lack of knowledge about the significance of heart attack symptoms is a critical factor when Maori and European people make decisions to seek medical care. The programme will be aimed at improving the recognition of cardiac symptoms and reducing delay time between onset of symptoms and presentation to hospital following an acute myocardial infarction.

### **Objectives**

1. To explore European and Maori women's recognition and understanding of premonitory and actual heart attack symptoms. This exploration will describe women's experiences of heart attack symptoms, what they believe is the cause of their symptoms, how they describe their symptoms to others and the length of time in seeking medical assistance
2. To determine in particular, why women may not take the appropriate action at the time of the acute event.
3. To determine differences, if any, in the above matters between Maori and European women and also between women and men from both ethnic groups.

4. As a consequence of the study findings, to be in a position to make recommendations to the Ministry of Health and The National Heart Foundation, if appropriate.

## **Thesis Structure**

Chapter One, Introduction - In this chapter the thesis topic has been introduced. An explanation of the study purpose has been linked to the reasons for conducting a qualitative study, the main reason being that the researcher wished to capture the myriad of social interactions surrounding care-seeking for heart disease symptoms, particularly for women. The aims, objectives and study population have been set out to establish the parameters for this research. The thesis structure is set out for the reader.

Chapter Two, Literature Review: Women and Heart Disease – The literature search strategy for both literature review chapters is described. This chapter presents the background literature as to why heart disease is a significant issue for women and some of the reasons for the lack of research on women and heart disease. The symptoms of myocardial infarction are described, together with gender and ethnic differences in symptoms. Perceptions of heart attack symptoms in women and Maori are identified and previous research on demographic and clinical predictors of delay are summarised. Previous research on psychological variables and theoretical models of symptoms perceptions are linked to a discussion of delay intervals for seeking care for relation to gender and culture diversity in responses to symptoms of heart disease.

Chapter Three, Literature Review: Theory Development - Part One covers heart beliefs and the symbolism and imagery of beliefs about the heart. There is some discussion of the changes in beliefs, meanings and perceptions of the heart. The review links literature from science, medicine, mythology and literary sources to establish women's role in the medical profession and their place in philosophical and medical debates. Superstitious beliefs about the heart influenced heart surgery and the review tracks the development of stereotypical images of men with heart disease. This section finishes with an examination of how stereotypes influence medical practice and a summary. Part Two examines the literature on gender and cultural factors. It discusses cultural constructions of gender and gender stereotypes and care

seeking for heart disease. The influence of cultural factors on health behaviours is identified. Some of the issues arising out of cultural influences on illness representations are discussed. Previous research on cultural factors influence illness representations is identified. Finally, Maori health rights in terms of the Treaty of Waitangi are described in conjunction with a definition of Maori cultural identity. A summary of the literature review concludes this chapter.

Chapter Four, Grounded Theory Rationale - This chapter addresses the underlying assumptions and rationale underpinning the grounded theory methodology used for this study. The characteristics, philosophic traditions, and ideological perspectives of qualitative research are introduced together with discussion about the researcher's assumptions. Grounded theory is defined in terms of its application to the research method highlighting the theoretical aspects of the interview process. The theoretical sampling technique, the sample profile and data analysis is explained. The data analysis is discussed in relation to the theoretical basis of creating categories for theory generation.

Chapter Five, Methodology - This chapter explains the study design, aims, objectives and methodological approach for the study. The qualitative data records have been acknowledged. The qualitative interview method is described in terms of question selection, ethical approval, data collection methods, the interview process and structure. The interview process has been emphasised as a way of gathering high quality data. Data analysis procedures are identified using the constant comparative method and causal-consequences model. Each stage of the theoretical development is discussed within the data analysis, and related to data collection methods, the analytic process and coding procedures. The methodological steps are related to the development of a theoretical model during the first part of the coding process. The strategies to ensure the trustworthiness of the data were described in terms of the consistency checks, stakeholder checks and reviews of empirical evidence. Finally, the analytic memo, independent category list, and tables illustrate the profile of participants in the study sample.

Chapter Six, Results: Symptom Perceptions - This chapter presents the findings from the participant data drawn from the initial context of their symptom experiences. Part

One identifies participants' delay times. Part Two covers the findings from the category 'people perceive symptoms in different ways'. This section contains recordings of the actual delay times, followed by descriptions of chest pain for both European and Maori participants that was not recognised as heart related. There is further identification of issues surrounding symptom interpretation, which encompasses beliefs about symptoms and descriptions of vague symptoms. Part Three covers the category 'people have different expectations about symptoms'. These findings identify how 'expectations about symptoms can arouse anxiety in different ways' and the 'confusion and uncertainty about symptoms' which includes the category 'lack of knowledge about thrombolytic therapy. Then there is a discussion of the participant data relating to both categories in this section. The delay times are discussed. Then participants' symptom perceptions are discussed in terms of their expectations about symptoms.

Chapter Seven, Results: Maori Dimension - This chapter presents the findings from the personal views of three Maori key informants that were interviewed to obtain some background for the Maori data collection. The chapter is in three parts covering three main themes. Part One covers Maori beliefs about the heart and modern medical treatment. This theme is explained and linked to the symbolism of the heart for Maori women. Part Two identifies traditional Maori health models, medicines and traditional Maori treatment for chest pain, which is reported from the point of view of the informants. The responses of Maori to bodily symptoms and chest pain are explained. Part Three presents the issues that influence care seeking. Doctors' communication styles were seen as important influences on Maori care seeking for heart disease symptoms. The key informant data is followed by a discussion of Maori perspectives on care seeking, Maori beliefs about the heart and the influences of poverty on Maori care seeking.

Chapter Eight, Results: Enduring symptoms – This chapter covers the findings from the participant data that were contained in the category 'people have different ways of enduring painful symptoms'. Part One covers the various ways that women endure their symptoms. There were some other differences when it came to enduring symptoms. European men considered the needs of their immediate families before receiving help. While Maori women's responsibilities for whanau (extended family)

members caused them to put up with symptoms for long periods. Maori men perceived that they had to endure symptoms as part of their authority or responsibilities within the whanau group. The discussion of this category incorporated how European and Maori women coped with symptoms using strategies handed down to them by wise women forbears. The chapter concludes with a discussion of how the participants' caring for others in the immediate social network led to lengthy periods enduring painful symptoms.

Chapter Nine, Results: Reassurance for Symptoms – This chapter concludes the presentation of the study findings. Part One presents the finding for the category 'people obtain reassurance in different ways'. Initially participants sought reassurance from family members and for Maori it was customary for them to seek support from whanau (immediate family and extended family). Some participants sought reassurance from friends. Consulting the doctor for reassurance revealed a complex set of dynamics where participants expected help but at times did not get the help they required. Some participants were misdiagnosed and women with uncommon symptoms were disregarded in the pre diagnosis period. Maori men participants tended to seek reassurance from the doctor for other chronic health conditions. Part Two covers the findings for the category, 'participants' take action in different ways'. The findings for this category showed that women participants care for others before they seek medical assistance. Maori women often took action and sought medical advice for other chronic health conditions that they experienced. On the other hand European men took a commonsense or straightforward approach to seeking medical assistance while Maori men were reluctant to take any actions for their symptoms. After Part One and Part Two the key findings are summarised. The final data map and the accompanying theoretical findings have been placed before the findings grounded in the data. A discussion of the final two categories covers the various ways that participants obtained reassurance. Then participants' self-treatment strategies are discussed. The final section in this chapter contains a discussion of patient-practitioner communication and dynamics. In addition participants' perceptions, the influence of age on visits to the doctor and patient centred interviews with doctors was identified in relation to the study findings.

Chapter Ten, Implications – This chapter covers the implications of the study findings based on the participant data. This chapter has three parts. The chapter covers the implications, conclusions and recommendations relating to the findings that make up the concept: ‘Recognising Women’s Responses to Heart Disease Symptoms: Different groups respond in different ways. The first part covers the categories that make up the meta-theory and elaborates on issues surrounding the participants’ experiences. The second part discusses the study implications in terms of what is known in the literature and what areas require further attention from researchers. The third part outlines the recommendations for making a difference in future research for women and heart disease. The implications drawn from the discoveries surrounding women’s symptoms and Maori perspectives about symptoms covers new perspectives to deal with education programmes to reduce care seeking delays for symptoms of heart disease. The strengths and limitations of the study are set out and discussed in the recommendations to conduct further research in this area. The concluding remarks contain recommendations for new education programmes that are targeted specifically for women. This chapter concludes with a set of recommendations for future developments to improve women’s recognition and responses to heart disease so that women receive prompt and appropriate care.

## **Summary**

This chapter has explained the research purpose and study aims. The reasons for undertaking the study have been discussed with reference to the empirical literature relating to both quantitative and qualitative research designs. The chapter section outlines the empirical reasons for undertaking a qualitative study. It explains the rationale underpinning the research design and study population. Then study aims and objectives were described. Finally the structure of the thesis is presented with a concluding summary.

## **CHAPTER II: LITERATURE REVIEW**

### **WOMEN AND HEART DISEASE**

*Statistics are like a bikini. What they reveal is interesting,  
but what they conceal is vital.*

Ruth Gottlieb, Wellington City Councillor (Orsman & Hurley, 1992)

#### **Overview**

This chapter commences with the literature search strategy and literature review summary undertaken for this study. The significance of cardiovascular disease as a global health problem for women is covered in the first section. This section discusses global women's heart diseases and stroke, the reasons why women's heart disease requires more attention from researchers, and differences between men and women. The second section reviews the literature related to myocardial infarction symptoms, gender and ethnic differences and perceptions of heart attack symptoms in women and Maori. The third section covers the demographic and clinical factors influencing delay which are discussed together with previous research on psychological variables as they relate to delay times and phases of delay. The final section discusses people's beliefs about symptoms, older people's responses to symptoms and previous research on illness perceptions and myocardial infarction.

#### **Introduction**

International cardiac researchers (Julian & Wenger, 1997), have identified a lack of medical knowledge about diagnosing acute coronary syndromes for women that in turn has led to a reduced rate of cardiac interventions among women. Lack of recognition and confusion about women's symptoms of heart disease created the need to gather more epidemiological data about the problem. The World Health Organisation (WHO) Mandate for Women and Heart Disease was established in 2001 to address the gaps in knowledge about the prevalence of heart disease in women worldwide. The literature review in this chapter covers medical, social and

psychological factors relating to delays in care seeking for acute myocardial infarction (AMI) symptoms. The background literature provided a clinical picture of long delays obtaining medical assistance because AMI or angina symptoms were not recognised by lay people. The longest delay times for reaching hospital with AMI symptoms are found to be for older people, especially older women and ethnic minorities such as African Americans and Maori. As this study emphasises women's responses to symptoms of heart disease discussion of the background material has included the Victoria Declaration on Women, Heart Diseases and Stroke, ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000). This declaration forms the basis of future global and national research initiatives designed by and specifically for women. This review incorporates the demographic and clinical predictors of delay, which includes previous research in this area. Chapter Three covers the literature review related to the findings and theory development. It complements the background material. This chapter takes a more in depth look at the historical reasons why women and ethnic minorities were not a significant part of the scientific cardiovascular investigations over the preceding thirty years.

## **Literature Search Strategy**

Searches were undertaken on the following electronic databases: CINAHL, Current Contents, EMBASE, MEDLINE, PsycINFO, and SocioFile. With each database different strategies were used but the coverage was basically the same. (See Appendix J for more details of the strategies used for each database and the time span covered.)

## **Background**

### **A significant women's issue - heart diseases and stroke**

According to the World Health Organisation report for 1999, cardiovascular disease is the leading cause of death in all developed countries with 16.7 million (8.7 million women and 8.0 men) deaths ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000)<sup>1</sup>

---

<sup>1</sup> Cheryl Campbell as a member of this group wishes to acknowledge the assistance of the conference convenors that have permitted her to use information contained in the Victoria Declaration to establish the background, and importance of global initiatives for Women and Heart Disease.

(New Zealand Ministry of Health, 2003). Heart diseases are fast approaching the same status in the developing countries. Cardiovascular diseases are the leading cause of death and disability worldwide for men and women over 65 years of age, despite declining mortality rates over the past thirty years. Changes to the rank order of global disease burden measured by Disability Life Adjusted Years shows that ischaemic heart will move from fifth place (1990) to first place by 2020 (C. Murray & Lopez, 1996). In many countries the actual number of deaths among women from cardiovascular disease is similar to men due to their longer life expectancy.

The impact on women's lives from deaths due to cardiovascular disease (CVD) and to infectious and parasitic disease (IPD) is shown in Table 2.1. The highest number of overall deaths from CVD and IPD are in India with death from CVD being 481,000 in women and 611,000 for men and 240,000 from IPD. China has the second highest number of deaths for CVD with 439,000 in women and 576 for men and 240,000 deaths from IPD. Countries with established market economies are the third highest with the number of deaths from CVD, 227,000 for women and 483,000 in men and 12,000 for IPD. Asia (226,000 women and 289,000 men), Former Socialist Economies (163,000 for women and 263,000 men), Latin America (174,000 women and 186,000 men), Middle Eastern (215,00 women and 285,000 men) and Sub Saharan Africa (211,000 women and 183,000 men) have similar death rates for CVD. While Sub Saharan Africa has a similar number of deaths compared to India from IPD (228,000). Other indicators of the impact on women are: being unable to remain in the workforce, concern about sustaining another heart attack or stroke, depression, anxiety, chronic pain or physical disability (Mosca et al., 2004). Another impact on women may be the physical limitations after experiencing a heart attack or stroke that may result in an inability to fulfil family roles, which in turn, might reduce her quality of life. In terms of the wider social impact cardiovascular disease results in high health care costs, lost productivity and a demand for more social services. The high prevalence of CVD risk factors for young and middle aged adults, both women and men combined with an aging population means that prevention and management of cardiovascular disease is a public health priority worldwide ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000). Higher rates of heart disease among young and middle-aged men have created the false conception among women and health providers that heart disease is primarily a

“middle-aged male disease”. Sharp (1998) states that coronary heart disease kills approximately 70,000 women in the United Kingdom each year.

**Table 2.1: Deaths (in 000s) due to cardiovascular disease (CVD) and to infectious and parasitic disease (IPD) in 30-69 year olds by sex and region, 1990**

<b>Region</b>	<b>Women</b>	<b>Women</b>	<b>Men</b>
	<b>IPD</b>	<b>CVD</b>	<b>CVD</b>
Established Market Economies	12	227	483
Formerly Socialist Economies	6	163	263
India	240	481	611
China	89	439	576
Other Asia and Island	140	226	289
Sub Saharan Africa	228	211	183
Latin America and Caribbean	48	147	186
Middle Eastern Crescent	85	215	285
<b>World</b>	<b>798</b>	<b>2201</b>	<b>3028</b>

Source: ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000)

A recent article in Time magazine reports that heart disease will kill one out of three women in the United States and Canada each year (Gorman, 2003). Recent statistical data shows that 500,000 women in the USA die from heart disease each year.

Women’s death rates have increased whereas deaths in men have decreased between 1979 and 2001 (N. K. Wenger, 2002). Lack of awareness in heart health issues that are specific to women has impeded progress in research and policy initiatives.

### **World Health Organisation mandate for women and heart disease**

According to Professor Ruth Bonita (2000) the World Health Organisation has a new focus on recognising the significance of coronary heart disease and stroke for women. Health planners have not systematically collected, disaggregated and analysed data by sex, age and socio-economic status. Medical research, epidemiological studies, many drug therapy protocols and medical interventions administered to women are based on

research solely on men. There has been little investigation or adjustment for gender differences ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000; Bonita, 2000; Wenger, 1997, 1998; N. Wenger, 2002).

McKinlay (1996) argues that epidemiological rates are socially constructed and rely too much on behavioural factors that affect the production of health data. In this view, epidemiologists do not take into account the effects of social structure or system influences in disease rates for human populations. He provided a case example where a woman health professional presented at hospital three times with classic heart attack symptoms (chest pain, numbness of her left side sweating and nausea). She was assertive and received three separate electrocardiograms (ECG's) but was sent home to take antacids and ulcer medications. She was admitted to hospital on her third visit. On the following day a cardiologist was reviewing ECG's without paying attention to gender and queried who the 36 year old was with the massive heart attack. McKinlay concluded that gender differences in heart disease could be attributed to how providers and the system respond as well as the biophysiology of patients and their reactions to events.

Ruth Bonita (2000) reports that for two thirds of the world's population there is no data for heart disease or stroke. Ongoing surveillance needs urgent attention because third world countries are still grappling with infectious diseases now an additional burden with the epidemic of heart disease and stroke. The new strategy for the World Health Organisation is to refocus, so as to encourage and support strategies to reduce risk factors and mortality rates from coronary heart disease and stroke for men and women. The World Health Organisation has a mandate to put more resources into gender as a factor in CVD. There is enough already known about the causes of coronary heart disease and stroke to make appreciable changes for women, throughout the world.

### **Why has women's heart disease lacked attention from scientific communities?**

To attempt to answer this puzzle, the researcher believed that it was vital to shift into a detective's role and trace information from three areas. Initially, the researcher found information about women's heart disease symptoms through a review of the

scientific literature to identify historical recordings in the medical history. At first, the researcher somewhat naively presumed that she would need to search medical books for the history of women's heart disease and the answers would magically appear. Well nothing was further from the truth. The medical historical texts made a couple of oblique references to potentially false angina symptoms in neurotic women, and that was all.

The lack of scientific information on women and heart disease made the researcher stop and consider where references could be found in related literature. The heart is an organ that occupies a special, symbolic place in everyday life. Any mention of the heart conjures up a range of images and meanings that are an intrinsic part of our inherited knowledge. The researcher reviewed literary, medical and psychological articles that tracked the origin of beliefs about the heart, where the beliefs came from and who manufactured these beliefs. The search was expanded to include, the extent to which beliefs about the heart influenced contemporary medical diagnostic protocols. The origins of heart beliefs were saturated in men's medical dialogue, which revealed superstitious beliefs about the heart.

The review showed a lack of information about women. The researcher closely examined literature from medical, literary, psychological, cultural and social spheres to find relevant information. What eventuated was that the researcher contacted a woman curator at the Auckland Art Gallery with expertise in art history. Following the curator's suggestions, a search was undertaken in the literary texts for ancient medical illustrations and any mention of women's roles or place in medical history. The final review was a woven history constructed from many sources. The following discussion is an attempt to piece together a history that included women thus rendering their place visible.

Julian (1997) and Wenger (2002) report that traditionally heart disease has been regarded as a man's disease, even though in older age groups women are just as likely to have angina or a myocardial infarction. Another reason for this neglect is that women's health issues have been centred on services exclusive to women such as breast cancer, menopause or reproductive organs. A recent review of information on women and heart disease between 1957-2000 showed that there was little information

specific to women and heart disease until the 1980's. An article in the 1960's focused on strategies for women to take care of their husband's hearts (C. L. Miller & Kollauf, 2002). The promotion and prevention of heart diseases and stroke among women can only be accomplished with attention to the realities of women's various roles with the family, community and the country. ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000; Mosca et al., 2004)

### **Differences in heart disease between women and men**

Coronary heart disease affects women approximately 10 years later than men. This may be due to the protective effects of oestrogen before menopause (Julian & Wenger, 1997). There is little evidence for this from studies of endogenous hormone levels (Khaw, 1997). Women are less likely to survive a heart attack. If women survive, they have an increased rate of re-infarction, heart failure and death. Some risk factors may affect women differently; for instance, women with diabetes have twice the risk of coronary heart disease and stroke than men. Elevated triglyceride levels are an independent risk factor in women and may be a better predictor of CHD than low-density lipoproteins (LDL) cholesterol levels. Women have additional risk factors such as oral contraceptive use in combination with smoking (a risk factor for stroke) and gestational diabetes (a risk factor for heart disease). Smoking rates are increasing for younger women in developed and developing countries, whereas previously smoking rates for women were lower than men ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000; Khaw, 1997).

### **Differences in diagnosis and treatment for women and men**

There is greater confusion in diagnosing coronary and non-coronary chest pain syndromes for women than men (Julian & Wenger, 1997). Referral to diagnostic tests and treatment may vary by sex. Women have smaller coronary arteries and more vaso-reactive diseases (for example Raynaud's phenomenon). These factors in turn might influence the impact of vasodilation therapy. Women are less likely to be referred for invasive investigations. For example, a lower proportion of women with CHD undergo angioplasty and coronary artery bypass surgery ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000; Wenger, 1997, 1998).

### **Social context of heart diseases and stroke among women**

The westernised formal health care system has placed women's health mostly within the domains of childbearing and reproductive problems. Health care partly reflects the roles given to women in the wider society, through childbirth and rearing children. Women's roles have drastically changed throughout the world and it is important to redefine women's health in wider terms (Orth-Gomer & Chesney, 1997). Women's health was defined at the Fourth World Conference on Women in Beijing 1995 as needing to incorporate the whole woman within the context of her life. This definition includes emotional, social, cultural and spiritual wellbeing within the biological, political and economic context of women's lives. It was used as a cornerstone for policy initiatives on women and heart disease. According to the Victoria Declaration (2000) inequalities include unequal access to basic resources, unequal access to primary health care, health programmes and policies that perpetuate gender stereotypes and inadequate and inappropriate health services.

Many things influence women's heart health and women's potential to develop heart disease. Achieving optimal cardiovascular health is severely impaired by socio-economic determinants such as poverty, education, culture, access to health services, the position and power of women in particular cultures and media influence. All of these factors shape women's views about themselves and their perceptions of those in positions of power (J. McKinlay, 1996). In many countries women are not represented at government or corporate levels and they lack influence in policymaking in their communities. Women are more likely to be represented in the lower ranks in the workplace in sex segregated, highly demanding positions with low control over organisational policies. While there are variations between countries and cultures women are likely to have primary responsibility for maintaining the home and family. The majority of women worldwide have to contend with poverty, illiteracy and other social factors, which are barriers to achieving optimal health. The active involvement of women in identifying and improving the key determinants for heart health is an important international and national priority.

## **The status of women in New Zealand**

The Ministry of Women's Affairs in New Zealand has provided the following report, which identifies gaps in New Zealand women's equality with men and suggests strategies to improve their status (*The status of women in New Zealand 2002: The fifth report on New Zealand's progress on implementing the United Nations Convention on the Elimination of All forms of Discrimination Against Women*, 2002). They report that women make up 51.3% of the paid workforce compared to 48.7% of men with 21.5 % of women's jobs being in service or sales occupations, clerks, technicians and other professionals. Men were more likely to be employed as trades workers, administrators, legislators, managers, plant and machinery operators, technicians and other professionals. Since 1996, there has been a strong growth in community, personal services, business and financial occupation for women. Women in most occupational groups earn 10% less than men. Women spend 4.8 hours per day in unpaid work compared to men's 2.8 hours. Women spend more time in all categories of unpaid work, housework, care giving, and purchasing services for their household or other unpaid work. Parliamentary representation of women in government has increased from 21% (1996) to 29% (1999) with two out of seven Maori members being women. Analyses of elected District Health Board membership in 2000 showed that 66 were women and 81 were men with 41 not disclosed. In 2000, 53% of women completed a degree in tertiary education compared to 52% for men. However, for life expectancy women do better than men (women 80.8 years compared to 75.7 years for men), with Maori life expectancy is 71.6 years women and 67.2 years men (1998-2000). Life expectancy increased as levels of deprivation decreased with 77.2 years representing the most deprived and 82.8 years the least deprived with 5.6 years difference (1998-2000). Women aged over 85 years were 50% more likely than men to be in residential care. Older Maori women are more likely to be widowed, living in a rural area and have a low income. Older women tended to have fewer resources than men, were more likely to be widowed, live alone, have a lower income, live in social or rural isolation and be caring for a frail partner or older parents (*The status of women in New Zealand 2002: The fifth report on New Zealand's progress on implementing the United Nations Convention on the Elimination of All forms of Discrimination Against Women*, 2002).

## **Coronary heart disease in New Zealand**

Coronary heart disease (CHD) is the most common cause of death in New Zealand in men and women and a major cause of morbidity. In 1998 the female age standardised rate of ischaemic heart disease (IHD) was 75.1 per 100,000 of the population with 157.9 per 100,000 for males (Segi world population). For Maori females the age standardised mortality rate was 118.6 per 100,000. In the group European/others the rate was 71.4 per 100,000 (New Zealand Ministry of Health, 2003; *The status of women in New Zealand 2002: The fifth report on New Zealand's progress on implementing the United Nations Convention on the Elimination of All forms of Discrimination Against Women*, 2002). In 1999, 6571 people died of coronary heart disease in New Zealand of whom 3344, (1496 women and 1848 men) died from an acute myocardial infarction (AMI). This data includes 256 Maori deaths (110 women and 146 men) from myocardial infarction (New Zealand Ministry of Health, 2003).

Traditionally, coronary heart disease is manifested in three ways: either angina pectoris (chest pain) or acute myocardial infarction (heart attack) and sudden cardiac death (cardiac arrest). New definitions of acute myocardial infarction have been established by the American Heart Association guidelines (Luepker et al., 2003): a definite AMI is diagnosed by a combination of cardiac signs and symptoms, ECG and biomarkers. Recently, a new diagnostic category has been established. Acute coronary syndrome (ACS) is a term that represents acute myocardial ischaemia and includes unstable angina, non-ST elevation myocardial infarction and ST elevation myocardial infarction (DeVon & Zerwic, 2002). It is also described as acute myocardial syndrome defined by a raised troponin T level. In the absence of troponin T the diagnosis is downgraded to possible myocardial infarction. All four conditions are almost always caused by atherosclerosis, a build up of fat and plaques laden with cholesterol in the coronary artery linings. Angina symptoms most commonly consist of a tightening or band of pain (lasting from one to 10 minutes) around the chest usually precipitated by physical exertion or emotional upset. An oral spray of nitro lingual under the tongue usually relieves it. Other less common symptoms are pain radiating from the chest down the left arm, and or around the back or sometimes shortness of breath. An acute myocardial infarction or heart attack is death of heart muscle, usually associated with a total occlusion of a coronary artery that supplies the heart wall. The symptoms of an AMI are usually severe chest pain lasting 20 to 30

minutes, often accompanied by other symptoms such as sweating, shortness of breath, nausea, vomiting or a feeling of impending death. Traditionally the symptoms of an AMI or ACS have been assumed to be the same for women and men. There is increasing evidence that there are gender differences in presenting symptoms of both AMI and ACS (Allan & Scheidt, 1996; DeVon & Zerwic, 2002).

Survival following an acute myocardial infarction is dependent on the severity of the event and how promptly the patient receives appropriate treatment. Prompt treatment for an AMI is particularly important when the patient is eligible for thrombolytic therapy for the occluded coronary artery (Allan & Scheidt, 1996). Most fatalities occur within the first hour after the onset of symptoms. Whilst thrombolytic therapy is most efficacious if given within the first six hours after the onset of symptoms, the magnitude of the benefit declines after the first hour (M. M. Ottesen, Kober, Jorgensen, & Torp-Pedersen, 1996; Yarzebski, Goldberg, Gore, & Alpert, 1994). The Brighton Study (R. Norris, 1999) reported that many people arrive in hospital too late to receive thrombolytic therapy (54% of 1090 patients received thrombolysis) or have died prior to hospitalisation. Norris (1999) documented that 74% of fatal events (1172 out of 1589 fatal events) happened out of hospital. Fatality rates from myocardial infarction in Maori have been 30-40% higher than for Europeans between 45 and 64 years old (Bullen, 1997). The death rate for Maori women in this age group was more than twice that of European women (Bullen, 1997).

Recent studies (Anonymous, 1988; M. M. Ottesen et al., 1996; Yarzebski et al., 1994) show most AMI fatalities occur within one hour after the onset of symptoms. If thrombolytic therapy is received soon enough it can alter the course of the infarction, limit the extent of the myocardial tissue damage and significantly reduce subsequent morbidity. The benefits of thrombolytic therapy are related to the interval between the onset of symptoms and administration of the drug (M. M. Ottesen et al., 1996). Patient delay is a major component in pre-hospital delay time for AMI symptoms (which is described as the total time from when the person first notices a symptom to their arrival at a medical clinic). Median delay times have been reported to range between two and six hours, but recent clinical trials (M. M. Ottesen et al., 1996; Yarzebski et al., 1994) report ranges from one hour up to 40 hours.

The single most modifiable factor in reducing mortality from myocardial infarction is delay in presenting to hospital after the onset of AMI symptoms (M. M. Ottesen et al., 1996; Yarzebski et al., 1994). The Auckland Regional Coronary or Stroke Study (ARCOS) (Doggen et al., 1993; Sonke, Beaglehole, Jackson, Stewart, & Stewart, 1996) was conducted in Auckland on all patients who experienced an acute myocardial infarction under the age of 65 in the years 1986 to 1992. This study showed that the median time from onset of symptoms to arrival in coronary care was 3 hours 25 minutes (Doggen et al., 1993). Women presented later than men 3.5 hours (range 1.3 hours to 6 hours) and 3.0 hours (range 1.6 hours to 6.0 hours) respectively (Sonke et al., 1996). Maori presented significantly later than Europeans within four hours (cumulative percentage 50.4% compared to Europeans 60.7% and Pacific Island people 60.4%) (Doggen et al., 1993).

The ARCOS (Doggen et al., 1993) study has shown no change in the delay time between onset of symptoms and hospital admission over the study years 1986 to 1992. Delay times are still disappointingly long despite the major medical advance of thrombolytic therapy during that time and its attendant publicity. Two factors are critical to reducing delay times for symptoms of an AMI. Firstly, the patient, his or her family and medical professionals need to recognise the symptoms of an acute myocardial infarction. Secondly, they need to have an understanding of the reasons for patient delay. It is essential that further research examines symptom recognition and delay behaviours before an appropriate educational programme can be instituted. If groups with prolonged delays in care seeking for AMI symptoms are to benefit from public education programmes, it is important to identify any gender or ethnic differences in symptom perceptions and delay behaviours.

### **Symptoms of myocardial infarction, gender and ethnic differences**

The classic descriptions of the symptoms of a myocardial infarction and angina are based on the questionnaires developed by Rose (1962). These questionnaires have been used as a basis for many research trials. The questionnaires were based however on a study of 30 men and 6 women for anginal symptoms and 15 men and no women for symptoms of acute myocardial infarction. In Goldberg's (1998) population based study of sex differences in symptom presentation associated with acute myocardial

infarction only 75% of women complained of chest pain (compared to 85% of men). Most studies of gender differences have been based on retrospective reviews of pre-existing databases. There were limited choices for coding of symptoms of an acute myocardial infarction (Goldberg et al., 1998; Rose, 1962) and in the latter case the presence of chest pain was a prerequisite for admission to the study. Unusual presentations can be missed by this technique and the true frequency of symptom occurrence and association is missed when hospital and ambulance reports are relied on for accurate symptom recording. A recent study (Baker & Koelmeyer, 1999) from the Auckland coroner's pathologist found that 12 of 67 patients who died from a myocardial infarction with cardiac rupture and who had consulted their doctor in the preceding two weeks had presented complaining of a "flu-like" illness and been treated accordingly. This is not a described symptom in any of the other studies.

No studies have been done to describe symptoms of acute myocardial infarction and angina in Maori people. It is therefore unknown whether there is any difference in symptoms observed and the language used to describe them in these communities. The proposed qualitative study will explore symptom descriptions experienced with acute myocardial infarction and angina in the study population, paying particular attention to any differences according to gender or ethnicity.

### **Perceptions of heart attack symptoms in women and Maori**

Surveys in North America have shown that most women do not perceive coronary heart disease as an important health problem that they are likely to face (Legato et al., 1997; Weaver et al., 1993; Wenger, 1997, 1998; N. K. Wenger, 2002). SoRelle (1999) reported that psychosocial factors are often dismissed and large numbers of women did not connect their painful symptoms to heart problems. In one American telephone based survey, 44% of the 1002 women interviewed believed that they were unlikely to have a heart attack in their lifetimes (H. Meischke, Larsen, & Eisenberg, 1998). Fifty-eight per cent of the women in this study perceived that their risk of breast cancer was the same or greater than their risk of heart disease. A further multiple centre study (1294 participants) by Meischke (2000) and colleagues showed that people who perceived they had bad health had a greater perception of their AMI risk. A family history of AMI and self-reported diagnosis of high blood pressure were significant predictors of AMI risk perceptions. Risk perceptions did not increase

with age and women who believed that heart disease was the leading cause of death had higher AMI risk perceptions than those women who answered the question incorrectly. Findings of gender differences in delays from the Global Utilisation of Streptokinase and Tissue Plasminogen Activator for Occluded Coronary Arteries (GUSTO) trial (Weaver et al., 1993) show that median times from symptom onset to admission and treatment were longer for women than for men, 2.0 hours versus 1.8 hours and 3.3 hours versus 3.0 hours respectively. Women delay substantially longer than men (Weaver et al., 1993). More recently Gibler and associates (2002) analysed delay intervals in the GUSTO-I and GUSTO-III in 27,849 patients where findings showed that the longest delays were for older people (64 years versus 60 years;  $P=0.001$ ) and more often female (35% versus 27%;  $P=0.001$ ), African American (6% versus 4%,  $P=0.02$ ) and diabetic (25% versus 16%,  $P=0.001$ ). This study found that people who arrived earlier had higher levels of education, professional occupations, and had private health insurance. Time to hospital arrival had not changed over seven years averaging 84 minutes.

Leslie and colleagues (Leslie, Urie, Hooper, & Morrison, 2000) examined the patterns of accessing care in England, for AMI and angina symptoms in 313 participants (85 women and 228 men). They found that 25% of the sample called for help within one hour of experiencing symptoms, 40% of participants delayed more than 4 hours, and 55% requested the attendance of a general practitioner. Most of the participants did not recognise the symptoms as emanating from the heart and perceived that they were not serious enough to call emergency services. One hundred and sixteen (30 women and 86 men) participants thought that the symptoms would go away. More women than men (65% vs. 51%;  $p=0.028$ ) initially contacted their general practitioner. A qualitative study of 22 (2 women and 20 men) participants' perceptions (Pattenden, Watt, Lewin, & Stanford, 2002) of AMI symptoms showed that six themes influence the decision-making process: appraising symptoms, perceived risk, psychological and emotional factors, use of the health system and the context of the event. These investigators concluded that knowledge of AMI symptoms is not enough to result in rapid action at the time of the event, as the social context surrounding a heart attack is complex and requires further investigation. The study shed some light into the decision making process for AMI symptoms, but findings cannot be generalised to other populations.

Another qualitative study (Schoenberg, Peters, & Drew, 2003) in the United States, using grounded theory explored older women's perceptions about time to treatment for cardiac symptoms. The sample of 40 participants was comprised of half diagnosed with CHD and half with chronic conditions considered to be risk factors for CHD. Study findings suggested that women's treatment decisions are linked to broader social and structural constraints. These constraints included confusion and uncertainty with symptom detection because symptoms were based on male norms. Other themes included problems with physician and patient interaction where physicians dismissed cardiac symptoms, competing social demands or responsibilities for family members and structural barriers in obtaining medical care such as lack of health insurance or lack of transportation.

Zerwic and associates (2003) interviewed 212 African American and non-Hispanic whites hospitalised for an AMI. Women did not significantly delay longer than men (2.0 vs. 2.5 median hours). African Americans delayed significantly longer than non-Hispanic whites (3.25 hours vs. 2.0 median hours). Participants' symptom experiences showed that 24% of women and 35% of men perceived that their symptoms were similar to their prior expectations of a heart attack. Women were less likely to perceive that their symptoms were heart related. When other variables in the multiple regression analysis were examined, ethnicity did not contribute significant variance to delay time. Ethnicity was a significant variable when delay time was categorised into one hour or less and greater than one hour because it is necessary to access emergency services to obtain thrombolytic therapy. African Americans were less likely to access emergency services (13% of African Americans compared to 35% of non-Hispanic whites) within one hour.

Table 2.2 shows that eight studies (Ashton, 1999; Campbell, 1998; Gibler et al., 2002; Robert Horne & Weinman, 1999; Leslie et al., 2000; Pattenden et al., 2002; Perry, Petrie, Ellis, Horne, & Moss-Morris, 2001; Zerwic et al., 2003) showed that participants recognised that their symptoms were heart related but it resulted in increased delays. Three studies (Bleeker et al., 1995; H. Meischke, Eisenberg et al., 1995; M. M. Ottesen et al., 1996) reported that symptom recognition decreased delays.

**Table 2.2: Reported effect of symptom recognition, medical consultation and self-treatment on prehospital delay**

Author	Sample number	Recognised symptoms as heart related	Medical consultation	Self treatment
Meischke et al. (1995)	n=2316	-	+	+
Bleeker et al. (1995)	n=300	-		
Ottesen et al. (1996)	n=5798	-		
Ashton (1999)	n=121	+	+	+
Leslie et al. (2000)	n=313	+	+	+
Campbell (1998)	n=20	+	+	+
Horne et al. (2000)	n=88	+		
Perry et al. (2001)	n=47	+		+
Pattenden et al. (2002)	n=22	+		+
Gibler et al.(2002)	n= 27,849	+		
Zerwic et al. (2003)	n=212	+	+	+

Symptom recognition, medical consultation and self treatment: + increase in delay, - decrease in delay

Five studies reported that medical consultations increased delay times (Ashton, 1999; Campbell, 1998; Leslie et al., 2000; H. Meischke, Eisenberg et al., 1995; Zerwic et al., 2003) and seven studies reported that self-treatment (Ashton, 1999; Campbell, 1998; Leslie et al., 2000; H. Meischke, Eisenberg et al., 1995; Pattenden et al., 2002; Perry et al., 2001; Zerwic et al., 2003) increased delays

### **Demographic and clinical predictors of delay**

Previous researchers (Cooper et al., 1986; K. Ell et al., 1994; Ghali, Cooper, Kowatly, & Liao, 1993; T. Hackett & Cassem, 1972; R. Norris, 1999; M. M. Ottesen et al., 1996; Rawles & Haites, 1988; Yarzebski et al., 1994) have focused on quantitative measures that include clinical indicators or sociodemographic characteristics that might predict prolonged delay such as age, socioeconomic status, ethnicity, education and gender. These studies showed that delay times were decreased for patients with haemodynamic instability, large infarcts or severe chest pain. Patients who had previous contact with medical services and those with a history of AMI or CHD did not have reduced delay times. Evidence (Cooper et al., 1986; Kathleen Ell & Dunkel-Schetter, 1994; Ghali et al., 1993; T. P. Hackett & Cassem, 1975; R. M. Norris, 1992; M. M. Ottesen et al., 1996; Rawles, Metcalfe, Shirreffs, Jennings, & Kenmure, 1990;

Yarzebski et al., 1994) from these studies suggests that cardiac education received in hospitals and clinics did not effectively reduce delay times. The pre-hospital phase of AMI received little attention. This was reflected in the results from the education campaigns that had limited success in reducing delay times (Cooper et al., 1986; K. Ell et al., 1994; Ghali et al., 1993; T. Hackett & Cassem, 1972; R. Norris, 1999; M. M. Ottesen et al., 1996; Rawles & Haites, 1988; Yarzebski et al., 1994).

Table 2.3 shows that five studies reported that age increased delay times, while six studies had lengthy delays for women, and only one study identified that ethnicity increased delay and one study reported no effect on delay times related to ethnicity. Two studies showed that age had no effect on delay times and two studies showed that there were no differences in delay times between men and women.

In the 1990's delays for reaching hospital with AMI symptoms were studied more frequently because treatments that preserve ischaemic myocardium and reduce infarction size offered a compelling reason to initiate early thrombolytic therapy.

**Table 2.3: Reported effect of sociodemographic variables on prehospital delay times**

Author	Sample Number	Older Age	Sex	Ethnicity
Alonzo (1986)	1102	+ -	+	
Yarzebski et al. (1994)	1279	+		
Ottesen et al. (1996)	5798	+	+	
Leizorovicz et al. (1997)	5469	+	+	
Cox et al. (1997)	2708	+	+	
Dracup et al. (1997)	317	+ -	+ -	+ -
Gurwitz et al. (1997)	2404	+	+	
Gibler et al. (2002)	27,849	+	+	
Zerwic et al. (2003)	212		0	+

Sociodemographic variables: 0 no effect on delay, + increase in delay, – decrease in delay

A consistent finding emerged where delay time was influenced by patients assessing and making decisions about health threats (Cooper et al., 1986; K. Ell et al., 1994; Ghali et al., 1993). A persons' decision time was found to be a major factor in the total delay time (Alonzo, 1986; Dracup et al., 1995). People with a history of congestive heart failure or angina could delay longer because they may not recognise that their premonitory symptoms are actually a heart attack. Conversely, patients who

experience sudden, severe pain may recognise that they are having a heart attack and summon medical help earlier. Individual differences in the way symptoms are interpreted leads to a variety of coping strategies. For instance, people may choose to travel to hospital by car if they believe their symptoms are not life threatening, or if they have severe pain, they may summon prompt medical assistance. During this period, median delay times (from symptom onset to hospital admission) for patients making decisions about their heart attack symptoms were: Bett and colleagues (1993) 1.2 hours (range 1-6 hours), Ottesen and colleagues (1996) 3.25 hours (5 to 95 percentiles range 0.67-40.0 hours) and Dracup and associates (1995) 6.4 hours (interquartile range, 1.9-19.9 hours).

Recent studies with large-scale clinical trials have found that older people especially older women, have prolonged delays (R. Norris, 1999; M. M. Ottesen et al., 1996; Yarzebski et al., 1994). Median delay times for these groups were: Ottesen and colleagues (M. M. Ottesen et al., 1996) 3.58 hours, Gurwitz and colleagues (1997) 6.0 hours or longer for people 65 years and older. More importantly, these later findings have shown decreases in delay times for people who have experienced a previous AMI or cardiac procedure (Gurwitz et al., 1997; M. M. Ottesen et al., 1996).

Health professionals, or simply learning through personal experience, could attribute this recent decrease in delay times to better provision of information. Further, the studies that documented these statistically significant findings were designed to validate thrombolytic therapy (Gurwitz et al., 1997; R. Norris, 1999; M. M. Ottesen et al., 1996; Yarzebski et al., 1994).

### **Previous research on psychological variables**

Delay in care seeking for heart attack symptoms presented an interesting dilemma for researchers because people in the community did not recognise that their AMI symptoms were serious and did not summon medical help promptly. Approximately 25%-50% of AMI patients delayed seeking medical care for more than six hours (Dracup et al., 1997). Researchers approached the problem in three ways: investigating people's decision making processes, performing audits to reduce waiting times in emergency wards before treatment was administered and establishing heart attack education programmes. The findings demonstrate that attempts to reduce pre-

hospital delay times were unsuccessful. Firstly, previous research (Cooper et al., 1986; K. Ell et al., 1995; Ghali et al., 1993; R. Norris, 1999; M. M. Ottesen et al., 1996; Yarzebski et al., 1994) revealed that the initial delays in people's decisions to seek care made the most contribution to overall delay times. Secondly, in Britain, studies of 'patient delay' were driven by service audits (Lori W. Kenyon, 1990; Wielgosz et al., 1988) that showed 'door to needle times' for hospital based thrombolytic therapy were reduced. However, public education campaigns did little to change care-seeking behaviour at this time (Cooper et al., 1986; K. Ell et al., 1994; Ghali et al., 1993). The third point of interest was that care-seeking behaviour was not changed if people had a prior history of AMI that gave them personal experiences of heart-related illnesses (R. Norris, 1999; M. M. Ottesen et al., 1996; Yarzebski et al., 1994). Researchers (Lori W. Kenyon, 1990; Wielgosz et al., 1988) began to concentrate their efforts on the psychological factors associated with patient delay (T. Hackett & Cassem, 1972; Lori W. Kenyon, 1990; Wielgosz et al., 1988).

Wielgosz and colleagues (1988) suggested that personality styles had the potential to predict delay; for instance, long delay times were found for people with angry or moody traits. However their research into this showed that personality factors have no effect on delay times. Nolan and Wielgosz (1991) conducted a structured interview with 45 AMI patients (7 women and 38 men). A cluster analysis was carried out on the data that included measures of Type A and Type B behaviour patterns, Anger-In, Potential for hostility and Behavioural Compensation for stress. Two groups were identified. They investigated personality factors, as well as other psychological variables such as symptom appraisal and accompanying symptoms in predicting delay. When these investigators compared two groups, ADAPTS (n=21) and MALADAPTS (n=24), a hierarchical discriminant analysis of coping behaviours found that the MALADAPT group had higher scores of anger and hostility but they did not predict delay. It was the coping behaviours to manage symptoms that showed patients in the MALADAPT group were more likely to ignore symptoms or "do something else" as a distraction from AMI symptoms, engaged in more relief-seeking behaviour, had greater perceived vulnerability to reinfarction, and longer delays in seeking medical assistance. Self-treatment activities such as resting or taking medication resulted in prolonged delay times (Nolan & Wielgosz, 1991; Wielgosz et al., 1988).

In this research delay intervals were split into high and low categories (> 4 hours and 31 minutes to 4 hours respectively) and 42% of patients waited more than four hours before coming to hospital. Maladaptive symptom-related coping behaviour was predictive of decision time (relief seeking and conviction of invulnerability to reinfarction adjusted  $r^2 = 0.46$ ,  $p < 0.01$ ). The study findings also showed that cardiac patients contact health professionals if their own efforts to relieve symptoms (resting or taking medication) are perceived to be ineffective. Nolan (1991) suggested that further studies should target the symptoms experienced in the prehospital phase. The findings were similar to the earlier findings of Hackett and Cassem (1972) where patients' perceptions of increased pain severity and recognition of cardiac symptoms decreased delay.

Kenyon and associates (1991) examined factors associated with symptom onset and hospital arrival among AMI patients. Median decision time was five hours (range 25 minutes to 62 hours). Delay times were not significantly associated with demographic or medical characteristics or Type A behaviour. Patients who were more capable of identifying inner experiences, emotions or body sensations sought earlier treatment. The studies by Hackett (1975), Kenyon (1991) and Wielgosz (1988) made an important contribution to current research because they identified people's ideas and coping strategies specifically for heart attack symptoms. They contribute to growing evidence to show that people's symptom interpretations can influence their care seeking behaviour. For instance Cameron and associates (Cameron, Leventhal, & Leventhal, 1993) investigated care seeking by comparing two groups. One group (care seekers) was selected if they initiated a visit to a physician for new health problems or a change in a previous health problem and the other group (controls) continued routine or follow up visits. The groups consisted of middle aged and older adults (the mean age was 60.9 years) matched for age, gender and health status. The findings show that care seekers reported more symptoms than matched controls, and perceived that their symptoms were more serious than symptoms reported by the controls. The presence of new or atypical symptoms did not trigger care seeking. The group who initiated a clinic appointment had symptom representations that were well developed as serious health threats, (Cameron et al., 1993) which influenced perceptions of their ability to cope and their subsequent care

seeking behaviour. In comparison, findings from a longitudinal study (Cameron, Leventhal, & Leventhal, 1995) revealed that new symptoms together with “ongoing life stress” were associated with increased care seeking. Conversely, people were less likely to seek medical care when they experienced ambiguous symptoms during the previous week in the presence of recent life stressors. In short, people’s beliefs about symptoms and the labels they give to symptoms can be seen as important influences on delay times for care seeking.

### **Delay times**

There are three intervals that are important in achieving the maximum benefit from modern advances in treatment within a few hours. These are: symptom onset to hospital arrival, hospital arrival and the time treatment is administered and the total time before treatment is received. Out of hospital delay time is usually defined as the interval between the first awareness of symptoms until hospital arrival. At least two factors influence reported out of hospital delay intervals. Firstly, prolonged delays where mean and median times differ widely because of the skewing effect made by individuals waiting several hours or days before seeking medical care and secondly investigators have differing criteria for assessing delay times. Studies (Dracup et al., 1995; Hofgren et al., 1988; R. Norris, 1999; M. M. Ottesen et al., 1996; Rawles & Haites, 1988; Rawles et al., 1990; Yarzebski et al., 1994) show that there is a significant variation in reported time between symptom onset and hospital arrival. Median delay times range from 1.2 hours to 6.4 hours (Dracup et al., 1995; Hofgren et al., 1988; Rawles & Haites, 1988; Rawles et al., 1990). A recent evaluation of presentation and treatment delays from a large scale clinical trial (Gibler et al., 2002) showed that symptom onset to hospital arrival intervals were 1.4 hours (range 0.9 hours to 2.3 hours) and 1.4 hours (range 0.8 hours to 2.3 hours), in hospital time to treatment was 1.1 hours (0.8 hours to 1.5 hours) which reduced to 0.8 hours (range 0.6 hours to 1.2 hours) and total time to treatment 2.7 hours (range 1.9 hours to 3.8 hours) compared to 2.3 hours (range 1.6 hours to 3.3 hours). This data shows little change in prolonged delay times in seeking medical assistance for AMI symptoms over time.

Researchers (Safer et al., 1979) have identified three critical stages of delay that contribute to an individual’s decision to seek treatment for distressing or acute symptoms: 1) appraisal delay - is the time when people appraise their symptoms as

signs of illness; 2) illness delay - the time a person takes to decide that they are ill until they seek medical care; 3) utilisation delay - the time between the decision to seek care and arrival time at a clinic or hospital. In a study evaluating factors influencing delay in seeking care at a hospital clinic researchers found that sensory perceptions, emotional reactions, beliefs about the cause of symptoms, strategies for coping with the illness all influenced delay. However, each stage of delay was mediated by different factors; consequently a single measure of total delay would be of limited value for understanding delay (Safer et al., 1979).

Table 2.4 outlines variations in study methodology, patient numbers, ascertainment of delay and pre-hospital delay times between 1986 and 1997. Pre-hospital delay was identified as problematic because mean and median times vary within and across studies.

**Table 2.4: Study methodology, numbers of patients, and prehospital delay times**

Author	Sample Number	Methodology	Data source for Delay	Median Hours, Minutes
Alonzo (1986)	n=1102	Comparison of two groups	Interview Medical Record	2.2. hrs
Doggen et al. (1993)	n=3088	Consecutive admissions	Structured Interview	3.30 hrs – 1983 3.55 hrs – 1984 3.30 hrs – 1985 3.10 hrs – 1986 3.24 hrs – 1987 2.55 hrs – 1988 2.50 hrs – 1989 3.15 hrs – 1990
Ottesen et al. (1996)	n= 5978	Consecutive admissions	Medical record	3.25 hrs
Gibler et al. (2002) GUSTO I	n=23,105	Enrolment	Medical record	1.4 hrs – 1990-93
GUSTO III	n= 4,744			1.4 hrs – 1995-97

### **People’s beliefs about symptoms**

The self-regulatory model (H. Leventhal et al., 1997; H. Leventhal et al., 1999) of illness behaviour provides a theoretical framework for understanding how illness and symptom-related beliefs influence coping strategies. (Figure 9. 2, shows a diagram of the self-regulatory model on page 215.) There are three stages in the self-regulative

process: (1) the mental representation of the health threat, which includes labelling of the symptoms of the threat, assessing the causes and consequences of the symptoms and perceptions of how the threat will manifest itself over time, (2) the coping procedure or action plan, in which a person initiates a coping strategy and (3) the appraisal stage in which a person assesses the coping strategy. Extensive research (Cameron et al., 1993, 1995; E. A. Leventhal, Easterling, Leventhal, & Cameron, 1995; H. Leventhal et al., 1999) indicates that people's beliefs about their illness are important determinants of their coping strategies. People organise their ideas about an illness within cognitive representations that include five primary attributes:

**Table 2.5: Attributes of the self regulatory model**

Identity:	The label and symptoms associated with the illness.
Time line:	How long the illness is expected to last
Causes:	Personal beliefs about the causes of the illness.
Consequences:	The expected effects and outcome of the illness.
Cure or control:	Expectations of how long it will take to recover from, or control the illness.

These attributes provide a framework that can be used to identify how people gather information to make sense of their symptoms, assess the health threat and drive the subsequent coping strategies (Cameron, 1997; Campbell, 1998; H. Leventhal et al., 1997; H. Leventhal et al., 1999; Moss-Morris, Petrie, & Weinman, 1996; K. J. Petrie, Weinman, Sharpe, & Buckley, 1996; J. Weinman, Petrie, Moss-Morris, & Horne). For instance, looking for other symptoms, waiting for pain to disappear or calling emergency services (Campbell, 1998). This self-regulatory (H. Leventhal et al., 1997; H. Leventhal et al., 1999) model has been usefully applied to illnesses, such as chronic fatigue syndrome (Moss-Morris et al., 1996), cancer screening (Cameron, 1997) and heart disease (Campbell, 1998; K. J. Petrie et al., 1996).

Empirical support for the illness representations on care seeking is provided by Cameron and colleagues (1993) and also by Petrie and associates (1996). Previous research (Cameron et al., 1993) on care seeking behaviours has found that it is not the physical manifestation of the symptoms that is the main factor in care seeking but

more importantly, how people interpret their symptoms. This interpretive process is supported by the contrast in findings for a care seeking and control group matched for age, gender and health status. More care seekers (68%) identified that their symptoms were caused by a specific disease compared to the matched control group (46%). This study found that care seekers were more likely than the control group to obtain prompt medical care because they judged their symptoms to be serious, and perceived that they were severe and uncontrollable.

Petrie (1996) reported that patient's illness perceptions after hospitalisation for a first myocardial infarction predicted some aspects of their behaviour. Patients were followed up in the recovery period. Although there was no difference in the medical seriousness of their myocardial infarction, patients who were more likely to attend rehabilitation had a significantly stronger belief that their heart disease was controllable or curable. Patients who believed that their heart disease was of relatively short duration returned to work earlier. In comparison, patients who believed that their heart disease was serious took longer before they returned to work, or recreational activities.

The self-regulatory model (H. Leventhal et al., 1997; H. Leventhal et al., 1999) links the process of how a person defines and labels the symptoms according to individual beliefs; personal illness experiences, and knowledge gained through contact with the media or others within their social environment. Illness representations and coping procedures are connected by "if-then rules". The "if" refers to illness identity and the "then" refers to beliefs or knowledge about expected consequences or alternatively, coping strategies. For example, if chest pain becomes severe, it usually motivates the person to call for emergency help (Campbell, 1998). The severe pain may have 'broken through' other coping strategies such as bed rest or self-medication, so that telephoning for assistance from emergency services represents a final attempt to obtain relief from the pain. This demonstrates the interdependence of illness representations and coping procedure; where procedures are shaped to 'fit' the perceived cause of the health threat (Campbell, 1998]; H. Leventhal et al., 1999).

However, beliefs about the origin of the pain may not change, even if the symptoms are severe. A cluster of symptoms, such as chest pain, nausea, shortness of breath,

could cause confusion about the origin of the illness. Symptoms may be interpreted incorrectly as a bout of 'flu' instead of being heart-related and the emergency services may not be contacted (Baker & Koelmeyer, 1999). Variations in patterns of health behaviour can be identified within the self-regulative framework using "if-then" rules. For example, people can classify their symptoms incorrectly and vary their coping strategies according to beliefs that they hold about themselves and the illness (H. Leventhal et al., 1997; H. Leventhal et al., 1999).

Research suggests that people can have highly inaccurate perceptions of heart attack symptoms (Campbell, 1998; K. J. Petrie et al., 1996). These misconceptions can lead to lengthy delays or eventual death if medical assistance is not summoned (Campbell, 1998). Previous research on illness representations has not explored cultural factors in relation to the self-regulatory model (H. Leventhal et al., 1997). Leventhal and Petrie (1997) state that symptom perceptions are monocultural constructs and coping strategies are culture neutral. In this view, differences are minimised to render them almost invisible. Durie (1994) criticised this perspective as a narrow focus on physical illness that outweighed interest in the person within their social and cultural environment. This study will address people's inaccurate perceptions about heart attacks so that future educational interventions can be designed to reduce care seeking delays in high-risk groups.

### **Age can influence beliefs about symptoms**

People's beliefs about symptoms are likely to change significantly over the course of their lifespan (E. A. Leventhal & Crouch, 1997). Koopman-Boyden (1993) describes old age in terms of chronological age and social age, where chronological age (the number of years lived) indicates diminished reserves whereas social age refers to older people's maturity and usefulness to society. Age-related changes in illness representations and coping strategies are likely to reflect the biological ageing process and changes in social roles. When people reach older ages, family and peer groups are more likely to talk about managing chronic illness and the increased likelihood of death amongst older people. The physiological changes brought about by ageing alter disease processes, which in turn, change symptom manifestation and response to treatment. Older people are potentially more at risk of life threatening diseases; their symptoms can be ambiguous, or develop slowly thus causing confusion about the nature of the illness.

Researchers using the self-regulatory model have found links between the symptom attributions and the coping strategies that relieve symptoms. These links take the form of cognitive rules, which are termed the “if-then” rules. Previous investigators have identified three “if-then” rules that influence symptom appraisal and coping strategies across the life span. The first rule is the age-illness rule that involves retrospective comparison of symptom experiences (H. Leventhal et al., 1999). The second and third rules are (the stress-illness rule and the shared-benign or singular-serious rule) (H. Leventhal et al., 1999) that involve appraisals of the external environment throughout the life span. Investigators (E. A. Leventhal & Crouch, 1997) have used the “if-then” rules to identify that older people tend to diminish the seriousness of symptoms that increases delays in care seeking. One study shows that older people are more likely to believe that either slow-to-develop symptoms are due to ageing, or ambiguous symptoms are the result of stress (Cameron et al., 1995). Leventhal and Crouch (1997) note that cardiovascular symptoms may present in a blunted form as people get older because the symptoms are slower to emerge and may be less severe (E. A. Leventhal & Crouch, 1997). Therefore, older people have to evaluate their AMI symptoms against a complex background of sensations associated with the biological ageing process and the increased likelihood of accompanying chronic conditions. Consequently, investigators (E. A. Leventhal & Crouch, 1997) have used the “if-then” rules (H. Leventhal et al., 1999) to identify distinct changes in illness representations that are related to age (E. A. Leventhal & Crouch, 1997; H. Leventhal et al., 1999).

While the “if-then” rules (H. Leventhal et al., 1999) influencing the generation of illness representations favour minimisation of health threats for older people, other strategies may nullify these rules. These strategies are risk aversion, consulting with other people, or gender differences. Older people are more likely to have an increased sense of vulnerability that has been related to an increase in health promoting behaviours (H. Leventhal et al., 1999). Evidence from other studies of care-seeking behaviour in older people shows that they are likely to discuss their symptoms with significant others or their peer group. Cameron, Leventhal and Leventhal (1995) compared 111 symptomatic patients who were interviewed before seeing their doctor and 33 people who experienced symptoms but did not visit a doctor. They found that

92% of the patient group had discussed their symptoms with another person compared to 61% of the controls (Cameron et al., 1995). Leventhal et al (1997) found that older people tend to minimise the perceived severity of symptoms after discussion with peers that could increase delay times.

Another study of care seeking among older people (H. Meischke, Eisenberg et al., 1995) found that delays in care seeking for older people were less than for middle-aged patients regardless of perceived symptom severity. Two different time intervals were used: appraisal delay (the time from first symptom onset until deciding that one was ill) and illness delay (the time from the decision one was ill until calling for medical care). Appraisal delays were shorter for older people in each level of symptom severity (mild, possibly serious, definitely serious). There were no reported age-related differences for mild or serious symptoms. However, middle-aged patients delayed substantially longer for symptoms they believed to be serious, and continued their daily activities (H. Meischke, Eisenberg et al., 1995).

Gender influences the burden of illness and symptom reporting with advancing age (E. A. Leventhal & Crouch, 1997). Leventhal and colleagues examined the relationship of age and gender; (Cameron et al., 1993; E. A. Leventhal et al., 1995) in two longitudinal studies, significant differences were found in illness burden (the number of serious illnesses and morbidity and symptom reporting). Women reported a higher number of symptoms than men, especially in middle age that is probably consistent with menopausal symptoms. Women showed more somatic symptoms of depression and more cognitive and somatic symptoms of anxiety than men. Men and women showed increased symptom reporting and a greater illness burden with advancing age. This study (E. A. Leventhal et al., 1995) showed that there was a cross over effect with increasing age where men more than 75 years of age had more illness severity, more symptoms and a greater illness burden. Conversely, women reported more physical impairment; more worry about getting sick and used health services more frequently (E. A. Leventhal & Crouch, 1997; E. A. Leventhal et al., 1995).

It is especially important to understand age and gender related differences in AMI symptoms and coping strategies given the evidence that older people have prolonged delay times (M. M. Ottesen et al., 1996; Yarzebski et al., 1994). Identifying these

mediating factors will provide a more complete understanding as to how age affects delay behaviours for AMI symptoms.

### **Previous studies of illness perceptions and myocardial infarction**

In 1997, a pilot study (Campbell, 1998) was conducted at Middlemore hospital. Findings from two studies can be compared to the pilot study data. Horne (2000); and Meischke (1995) found that alternative symptom attributions were the most frequently mentioned reason for not seeking medical care. The findings are similar to findings in the pilot study (Campbell, 1998) where most of the participants did not believe that their symptoms matched their prior expectations of a heart attack. Horne et al (2000) found that people were more likely to delay for longer if their symptoms had not matched their expectation of a heart attack (mean 1=558 minutes, mean 2 = 272 minutes; t-value =1.72, p<0.05, 1 tailed). While Meischke (1995) defined the dependent variable as the first thing people had done in response to symptoms. The most frequently mentioned reason for not dialling 111 pertained to the illness representation. For instance, only 7% of people called 111 immediately, because people thought that symptoms would disappear, or symptoms were not severe enough (H. Meischke, Ho, Eisenberg, Schaeffer, & Larsen, 1995). The Brighton study (R. Norris, 1999) and the Middlemore pilot (Campbell, 1998) reported that people were more likely to delay for longer if their symptoms had not matched their expectation of a heart attack.

The sample of 20 participants was taken from 45 consecutive admissions for first acute myocardial infarction to the coronary care unit. A retrospective structured questionnaire developed from work in the Brighton study (R. Horne et al., 2000; R. Norris, 1999) was used to interview participants. The study (R. Horne et al., 2000) was designed to measure ethnic differences, symptom perceptions and delay times from symptom onset to arrival at hospital (Campbell, 1998). There was a 2% error in hospital recording of ethnicity. Median pre-hospital delay time was 3 hours 17 minutes (range 30 minutes to 22 hours 20 minutes) while mean prehospital delay time was 6 hours 2 minutes. Seventy per cent of participants experienced symptoms prior to their heart attack. The majority of participants did not recognise that their

symptoms were heart-related and most of the participants (n=17) thought their heart attacks were different from their expectations (Campbell, 1998).

People's attitudes about going to hospital ranged from relief and optimism, to reluctance or embarrassment about obtaining medical care. People that delayed longer carried out self-treatment strategies such as using cough syrup, herbal remedies, or painkillers. People using these strategies believed that their symptoms were caused by influenza or bronchitis. Alternatively, if they believed they were experiencing angina pain they used angina spray. Some participants continued these self-treatment activities even after summoning the emergency services. Coping strategies such as contacting local health services and self-treatment with patent or prescribed medication were directly associated with inaccurate perceptions about the cause of the symptoms (Campbell, 1998).

The Middlemore pilot (Campbell, 1998) findings were not statistically significant and could not be compared with local studies. In 1999, a study of 'patient delay' with 47 participants (9 women and 38 men) by Perry and colleagues (2001) was carried out at Auckland hospital. This study examined symptom expectations, the affect of having a family member present and self-treatment behaviours. The mean (SE) and median pre-hospital delay times were 15.3 (4.1) and 4.0 hours respectively. The majority of participants (74%) had consulted with another person about their symptoms. Eighty one percent of participants had treated themselves before seeking medical assistance. This research study builds on the first Middlemore pilot (Campbell, 1998). It addresses the need for further research on inaccurate perceptions of heart attack symptoms for women and ethnic groups with prolonged delays.

It is predicted that symptom perceptions drive coping strategies (Campbell, 1998; R. Horne et al., 2000; H. Leventhal et al., 1997; Moss-Morris et al., 1996; Perry et al., 2001; Keith J. Petrie & Weinman, 1997; John Weinman, Petrie, Sharpe, & Walker, 2000). When people formulate alternative interpretations of their symptoms they choose an action to relieve symptoms that fit their symptom perceptions. They may take alternative actions (for example, self-treatment for indigestion) to relieve the symptoms rather than seek emergency care. It was proposed that alternative actions

can be identified before an acute event and interventions can foster accurate expectations about symptoms, thus reductions in delay times can be anticipated.

## **Summary**

This chapter provides the background literature for this study. The aims and objectives for the study have been informed from the background literature on care seeking for AMI symptoms. This chapter shows that findings from previous researchers have identified: medical determinants, delay intervals, sociodemographic and psychological factors related to pre-hospital delay. Comparison of variables across medical, social and psychological is difficult because there are differences in sample sizes and study methodologies. Investigators have not found a consistent explanation of pre-hospital delay for heart attack symptoms and patient decision times have not significantly decreased over thirty years (Dracup et al., 1995; R. Norris, 1999; M. M. Ottesen et al., 1996; Rawles & Haites, 1988; Yarzebski et al., 1994). Large-scale clinical trials (R. Norris, 1999; M. M. Ottesen et al., 1996; Yarzebski et al., 1994) have documented statistically significant findings that older people, especially older women have prolonged delays. Empirical support for the self-regulation model of illness behaviour (Campbell, 1998; R. Horne et al., 2000; H. Leventhal et al., 1997; Moss-Morris et al., 1996; Keith J. Petrie & Weinman, 1997; John Weinman et al., 2000) shows that people's beliefs about AMI symptoms influence their care seeking. Previous studies of illness perceptions and myocardial infarction (Campbell, 1998; Keith J. Petrie & Weinman, 1997) have justified the need to recruit a study sample that includes women, ethnic minorities and older people. The inclusion of specific numbers of women and ethnic minorities for the study is reflected in the study sample. Delay times will be recorded to make it possible to capture mediating influences in each part of the care-seeking process. This chapter has justified the need to explore gender and cultural differences in responses to heart attack symptoms. It has provided the background information that complements Chapter Three. The next chapter contains the second part of the literature review, which has been driven by the study findings. It examines more closely the role of beliefs about the heart together with a discussion of gender and cultural factors.

## CHAPTER III: LITERATURE REVIEW

### THEORY DEVELOPMENT

*My experience in the colony shows me that the most solidly educated women are the most useful in every department of life, and that so called 'feminine refinement' is fatal to female usefulness.*

Jane Maria Atkinson, writing to her old school friend Margaret Taylor, in 1870  
(*Quotable New Zealand women*, 1994)

*Being a woman I am not more than man nor less.*

Mary Stanley, Poet and teacher (*Quotable New Zealand women*, 1994)

#### Overview

This chapter has contributed to the theory development of the study findings. It discusses the literature from literary, mythology, scientific and medical sources that links beliefs about the heart to the absence of women from the debate. The rationale for this chapter is to show the complexities that lay behind commonplace beliefs about the heart and the intricacies of cultural belief systems which impact on care seeking behaviours for distressing symptoms.

This chapter is in two parts. Part One discusses heart beliefs. The historical symbolism of beliefs about the heart demonstrates how the changing beliefs about hearts have been a major influence on, and have directed, diagnostic and medical practices. The absence of women from the debate in philosophic and scientific matters has been identified through references from a wide body of literature. Information from scientific, literary, mythology and medical sources has been compiled to make women's lives visible in a historical way, and includes the few references to women relating to heart disease. Part Two examines the social constructions of gender and culture. Gender is defined in terms of the cultural constructions of gendered experiences. The development of stereotypes for heart disease is discussed, because they continue to influence women and their doctors' decision making about heart disease symptoms, and subsequently impact on access to medical care, in contemporary times. Culture is defined and discussed in relation to

the influence of cultural factors on both individual and collective illness beliefs. The chapter is summarised and a literature review summary is placed at the end of this chapter.

### **Part One: Heart beliefs - Introduction**

The origin of cultural beliefs is important because traditional beliefs about symptoms directly influence people's coping strategies. An important article by Kay (1993) traced cultural beliefs about the phenomenon of "fallen fontanelle" (a condition where the membranous space in an infant's skull becomes concave as the result of dehydration) back through time. This article provided some evidence that locating where the beliefs had originated in the first place was important for understanding how these beliefs influenced symptom perceptions in contemporary times. It reinforced the researcher's view that if she was to tackle the new study findings in an effective way, she had to establish the origins of western beliefs about the heart. The complexity of gender and cultural issues is covered by outlining some of the difficulties in separating individual representations and those representations that are held by cultural groups. This is followed by discussion of how cultural factors influence illness representations. Finally, a definition of Maori cultural identity sets the scene for the cultural differences in beliefs and behaviours related to Maori participants' perceptions of heart disease in this study.

#### **The influence of symbolism and imagery on beliefs about the heart**

When researchers study heart conditions and make recommendations for lifestyle changes to benefit the heart, it is assumed that this process is based on purely scientific knowledge. Health professionals are presumed to be experts with an objective viewpoint. Doctors are portrayed as detached observers of the biological mechanisms of the heart. It is widely believed that clinicians do not have superstitious beliefs about the heart. Lay people, especially women or ethnic minorities, may be deemed ignorant about heart disease, or when they do not comply with health messages or prescribed treatment regimens are quickly labelled non compliant. The historical literature from approximately 2000 BC until modern times post 2000 AD shows that both doctors and their patients possess superstitious beliefs about the heart. These beliefs shape the stereotypical images of male executives who

collapse and die after experiencing a heart attack. Stereotypical labels and beliefs reinforce public perceptions that heart disease is ‘a European middle-aged man’s problem’.

The heart symbol has been found to be the most powerful human image in many cultures. It represents a symbol for cultural organisation and universal understanding (Grassi, 1985). This traditional symbol is used to convey love, courage, strength, weakness and sadness. In both Eastern and Western medicine, the heart was seen as the centre of life, intelligence and body heat. Beliefs about the heart can be traced back to Eastern society. Hwang Ti, the “Yellow Emperor” in 2000 BC, is thought to be the author of the *Nei Ching* (Book of Medicine) (Margotta, 1967). This Chinese medical work states that all of the blood in the body is:

under control of the heart and regulated by it (Margotta, 1967, p. 42).

Chinese philosophers viewed the heart as the ruler of Shen (spirit) where health was perceived to be a balance of energies in the body. Two forces of energy were: Jing the essence of organic life, and Qi the quickening of matter into energy. The heart was considered to be the storehouse of Shen, which ruled the human desires to explore create or live life, freely (Kidd & Wix, 1996). Margotta (1967) reports that the *Nei Ching* (Chinese book of medicine) presents the major organs in a picturesque, symbolic form.

The heart is king, the lungs are his ministers, the liver is his general, and the gall bladder his justice, while the spleen governs the five senses and three hot cavities eliminate waste matter, namely thorax, abdomen and pelvis (Margotta, 1967, p. 42).

In Western society, the heart has intrigued philosophers, poets, theologians, thinkers and dreamers throughout time (Grassi, 1985; Kidd & Wix, 1996; R. Reichbart, 1981). Ancient philosophers, physicians and theologians, believed that the heart was the central organ anatomically, physiologically and psychologically. It was considered to be not only part of the physical body, but also the seat of the emotions, the intellect, volition, and moral life. Christian theologians viewed the heart as the point of contact

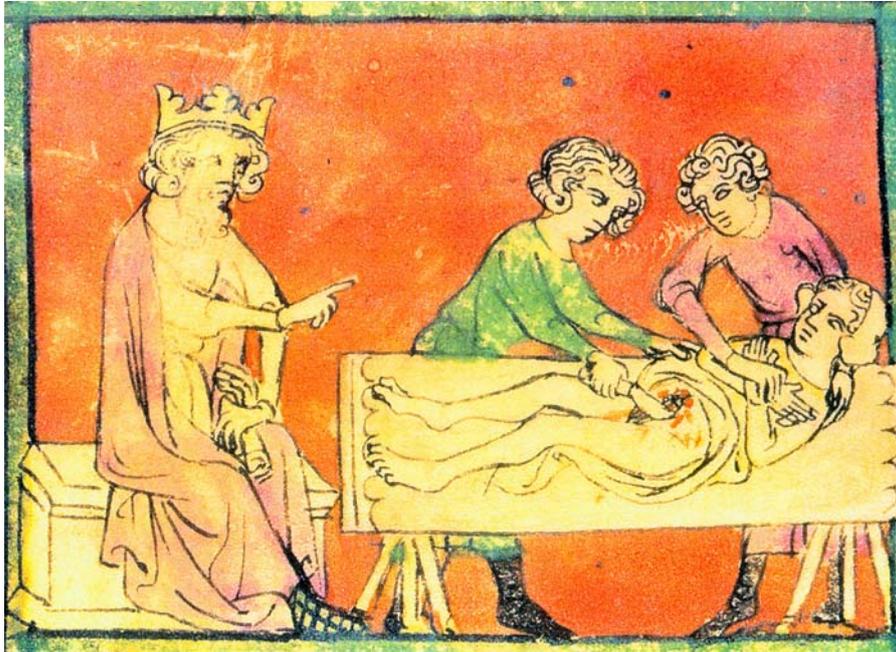
with God and the equivalent of the personality. According to Milgrom (1985) there are 850 entries of the word heart in the bible. References to the heart in the bible show that there was psychosomatic unity in biblical times people were one, where the heart and spirit were viewed as having the same functions. It is the controlling instrument regulating the ruah (Spirit) so that the nephesh (soul) may function properly and symbolises the power of God. It is portrayed as the hidden member that is the deepest level of personality, conscience or organ of understanding and knowledge (Exod.35: 21; Ps78: 8 – Vocabulary of the Bible) (Rowley, 1958). It is important to identify what people understand by references to the heart. The following quotations illustrate changing emotions and behaviour using heart metaphors from 2500 years ago:

- Proverbs 12:25 Anxiety in a man's heart weighs him down
- Proverbs 13:12 Hope deferred makes the heart sick
- Jeremiah 4:19 My anguish my anguish! I writhe in pain, my heart is beating wildly
- Jeremiah 23:09 My heart is broken within me all my bones shake
- Ezekiel 36:26 A new heart I will give you and I will take out of your flesh the heart of stone and give you a heart of flesh.

The heart was also a political metaphor it was linked to the centre of political activity. The centrality of the heart expresses the evolution of a state governed by a king in the fourteenth century. The monarch was the most important being in the state and this created centralisation where every activity took place around the king (Le Goff, 1989).

In Figure 3.1, the picture shows the power of the kingly figure directs the surgical exploration of the woman's body.

Figure 3.1: This painting is called Nero supervises the dissection of his mother Agrippina. It depicts a King with his gold crown symbolising political power as well as control over the woman's death and subsequent defilement of her body (Le Goff, 1989, p. 41)



Contemporary definitions of the word heart contain meanings that include these ancient beliefs. Two main definitions are:

[a] hollow muscular organ keeping up the circulation of blood by contracting and dilating...breast, bosom, mind, intellect seat of innermost thoughts (Fowler & Fowler, 1962, p. 460)

The image of the heart as a symbol of love (as shown in illustration 3.2) is everywhere in popular culture in poetry, paintings, love songs, literature, myths and legends.

Figure 3.2: Symbolic use of the heart shape



The heart shape has been used by artists so often that we take it for granted (Kidd & Wix, 1996; Milgrom, 1985; R. Reichbart, 1981). Reichbart (1981) has identified some of the characteristics of the heart that contribute to the rich symbolism surrounding this organ. These characteristics demonstrate the links between the heart's physical function to heart symbolism.

1. The heart is a unique and vital organ in relation to other internal organs. The heartbeat is a sign of life. An individual can become aware of the heartbeat functioning inside the body; the absence of a heartbeat in another person's body is a sign of death.
2. The heartbeat is not generally within conscious control of the individual (compared to breathing associated with the lungs).
3. The heartbeat can fluctuate greatly. The heart is subject to dramatic malfunctioning that may cause a fatal collapse. It can be affected by physical exertion, emotions, and internal and external stimuli.
4. The heart can be vulnerable to physical attack. Ancient physicians regarded wounds of the heart as fatal.
5. The heart is situated beneath the left breast in a human body. The heart of a mother lies in close proximity to a mother's breast

Any of these characteristics can influence in a symbolic way people's attitudes to the significance of anything to do with the heart. Our perception of centrality of the heart is constantly reinforced in daily conversation in the many ways we invoke this organ. Expressions such as heartthrob, heartache, heart broken, warm-hearted, heartless cold-hearted, stout hearted convey messages that are assumed to be metaphoric. These expressions have their roots in medical meanings related to empirical observations from ancient medical theories (McMahon, 1976; Sanne & Wenger, 1992).

### **Changes in beliefs and meanings**

The earliest mention of the heart in medical texts is the Hwang Ti (2000 BC) treatise about the circulation of the blood. The blood flowing continuously under the control of the heart is regarded as a near guess. Dissection of the dead was prohibited in Chinese society, which influenced the importance of the heart. The Nei Ching presents physiology in a manner that illustrates the heart as central to both mind and body. Hwang Ti is also noted for recognising the link between mind and body, stating that when people's minds are closed, they are more likely to have diseases (Allan & Scheidt, 1996; Margotta, 1967).

The blood circulation and identification of the pulse was described in an Egyptian papyrus (1500 BC). The character and frequency of the pulse was thought to be an indication of a person's health (Margotta, 1967). Ancient philosophers (Margotta, 1967) viewed health as a harmonious balance of heat and cold in body temperature and temperament. Changes in body temperature corresponded with changes or movement in the heart or soul. Heat and cold were related to the expansion and contraction of the heart and blood. An increase in body heat was thought to be the result of anger, which was thought to expand the blood and create a red complexion whereas fear was believed to contract the heart and chill the body and create a pallid complexion (McMahon, 1976). The ancient philosopher Hippocrates associated heat and cold with four humours (blood, phlegm, yellow bile and black bile) (McMahon, 1976) and linked the pulse to movement of the blood vessels and the heart. The notion of temperature was the basis for a theory of temperament with four humeral types, sanguine, phlegmatic, choleric and melancholic. Hippocrates did not perceive the heart as the seat of understanding but believed that it was particularly sensitive and easily affected secondarily. The pulse beat was linked to activity of the soul and vital spirits housed in the heart influenced its function. If the soul was violently affected, for example, if anger was provoked, changes in muscle tone were said to follow the heart's action directly. Some ancient philosophers considered that the heart was a source of nerves and the brain and nervous system were not considered important to animal life. It was the cardiovascular system that governed vital functions (McMahon, 1976).

Aristotle (384-322 BC) described the heart and blood vessels in relation to the pulse (Margotta, 1967). He attached great importance to the heart as the source of intelligence and body heat. He believed that veins contained blood and arteries contained air because dissection of the body was not allowed. Spirits located in the left ventricle gave heat, life and sensory messages to appropriate parts of the body. While Galen (cAD130-200) had complex views about the blood circulation and influenced medical beliefs about the heart for approximately 1500 years. He considered that the arteries contained blood not air and that there were two systems. The venous system centred on the liver and provided nutrition to the whole body. The arterial system was based on the heart and concerned with body heat. The two systems were perceived as being connected through pores in the interventricular septum. The movement of the blood was described as a tidal ebb and flow controlled by the liver, heart and the brain. Food passing the intestines was absorbed as chyle into the liver where imaginary essence called the natural spirits was added which was considered essential to maintain life (Margotta, 1967). The blood and natural spirits were transferred around the body by veins. Vital spirits derived from the heart were responsible for movement and animal spirits (animus) from the brain were responsible for sensation and movement. The heart was considered to be a furnace producing body heat. Heart activity was perceived as autonomous because it harboured the soul (Margotta, 1967; McMahan, 1976). An Arabian physician, Ibn An-Nafis (1210-88) challenged Galen's views. He declared that there was no opening between the two ventricles because blood would pass into the spirit and destroy the essence. Leonardo Da Vinci (1452-1519) dissected the heart and described it has having four chambers not two, but he was unable to clearly describe the vascular system (Margotta, 1967).

The Dark Ages are a disputed historical period. A general consensus among historians about actual dates for the Dark Ages was that they occurred around 500 to 1000 AD. In the Dark Ages, Christianity was the guiding force where flesh was a source of evil and stood apart from good that emanated from God. Health and diseases were subject to the influences of God the Healer or Satan the Devil. Prayers of faith were used to heal the sick. During the Renaissance physicians reverted to Galen's understandings of vital spirits. Heart and respiratory rates were important indicators of health or disease. It was believed that various humours created temperature changes in the body and this process manufactured emotions. The heart

was perceived as the source of emotions. Purity of heart was associated with purity of the blood. Movement of the heart was considered purposeful. If a man became angry his blood was directed outwards to the muscles for fighting. At this time the theory of temperament was that different personalities corresponded to different types of hearts (Margotta, 1967; McMahon, 1976).

### **Changing perceptions about the heart**

William Harvey (1965) was the founder of experimental physiology and discovered that the blood moves in a circle. He described how this process occurred through the phenomenon of systole contraction of the heart walls as they emptied of blood, and diastole, where the cavities dilated as they filled with blood.

Although there is nothing more uncertain and unquestionable, then, than the doctrine of spirits.....it would appear therefore, that all spirits were neither aerial substances, nor powers, nor habits, and that all were not incorporeal....It is therefore the same blood in the arteries that is found in the veins, although it may be admitted to be more spiritous, possessed of a higher vital force in the former than in the latter; but it is not changed into anything more vaporous or more aerial as if there were no spirits (Harvey, 1965, p. 118).

He challenged the concept of spirits inhabiting the heart by advocating that the heart was a pump. This discovery challenged traditional cardiovascular psychosomatic medicine. It paved the way for mind-body dualism where the heart was described as a mechanism and the soul was separated from biological functions. In contradiction of this knowledge he believed that fertilisation of the embryo was through a mystical, metaphysical process from an incorporeal agent. Harvey's discovery about circulation has permeated medical thought with a continuing belief in mind-body dualism. He wrote about the heart using the masculine metaphor of a king as a central organ within a man's body, thus rendering women's bodies invisible and excluded from the debate. However, he did observe that the emotions of pain, joy or hope affected heart rhythms (Allan & Scheidt, 1996). Contemporary medical theory needs to take cognisance of both mind and body so that the role of emotions and beliefs, and

how they influence perceptions of heart symptoms is taken into account (Harvey, 1965; Margotta, 1967; McMahan, 1976).

### **Women's place in philosophical and medical debates**

Contemporary work by Spelman (1982) reports that philosophers have had little to say about women and most references have been typically “nasty, brutish and short.” Women have not been considered central to intellectual debate about philosophical doctrine and references to them have been made in short essays or as unofficial asides. Western civilisation has not celebrated the body and women have traditionally been associated with their bodies and bodily functions (Spelman, 1982). Recent literary work such as this reinforces for the researcher that even when women are present in the text, the actual interpretations need to be carefully vetted for male interpretations of women's bodies or women's state of being. It was much harder to gain any formal understanding of women's historical views about their own bodies. After a search through medical databases, which revealed little and what information there was, had been written by men.

Two significant historical texts written by women describe women's position in society. In Florence, in the early Renaissance period, women remained under the legal political and economic control of men who were perceived as stable figureheads (Klapisch-Zuber, 1985). Women were not considered permanent fixtures in family lineage. They were often widowed at young ages, remarried and were obliged to leave their children, who belonged to the lineage of the father. Young widows would have to have tenacity and courage to resist family pressures. It has been reported that some women, very few, did succeed in gaining their independence. Klapisch-Zuber (1985) discussed the fate of two women at that time. Umiliana dei Cerchi wished to live her life in holy seclusion and Tancia Bandini wanted to enter a convent. Umiliana succeeded in her desire and was subsequently beatified, while Tancia failed and remained a housewife. There is no way of knowing just how widespread the desire not to marry might have been.

Translations from *The Book of the City of Ladies*, written by Christine de Pizan, (1982) is a remarkable work in terms of its observations about the inaccurate statements and male interpretations regarding women's bodies. Marina Warner wrote

the foreword passage in collaboration with Earl Richards who did the first translation of this work. The book sheds some light on women's view of men's writings. The following excerpt was translated from French and neatly contradicts the views of male dominated societies in the 14<sup>th</sup> and 15<sup>th</sup> centuries. The criticism of men is couched within imaginary conversations.

I know another small book in Latin, my lady, called the *Secreta mulierum*, *The Secrets of Women*, which discusses the constitution of their natural bodies and especially their great defects.

She replied, "You can see for yourself without further proof, this book was written carelessly and coloured by hypocrisy, for if you have looked at it, you know that it is obviously a treatise composed of lies....For since women can clearly know with proof that certain things which he treats are not all true, but pure fabrications.....It was done so that women would not know about the book and it's contents, because the man who wrote it knew that if women read it or heard it read aloud, they would know it was lies, would contradict it and make fun of it (de Pisan, 1982, pp. 22-23).

Another imaginary conversation refers to the suitability of women to be educated in the arts and sciences. In this fictitious conversation, Christine asks Reason whether God has ever wished to ennoble the mind of woman with the loftiness of the Sciences; and reason's answer:

If it were customary to send daughters to school like sons, and if they were then taught the natural sciences, they would learn as thoroughly and understand the subtleties of all the arts and sciences as well as sons....just as women have more delicate bodies than men, weaker and less able to perform many tasks, so do they have minds that are freer and sharper whenever they apply themselves (de Pisan, 1982, pp. 62-63).

Certainly, these writings are absent from traditional medical debate, but they are vital in providing a women's perspective about the origins of scientific thought and knowledge. The readings demonstrate three facets of patriarchal control over

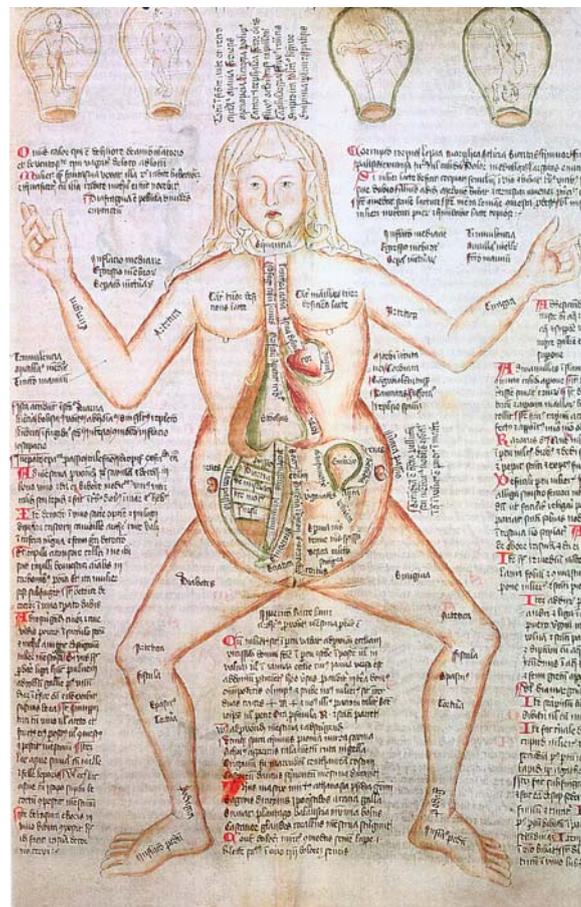
women's lives: (a) Men's economic control over women, through possession of women's dowries or land as the result of politically arranged marriages to increase men's wealth or status. (b) Male ownership of their bodies and their fertility, as mentioned previously where young widows were remarried and bereft of their children for men's strategic advancement. (c) Limited options to attain independence in their lives, other than religious seclusion.

In order to review men's historical interpretations of women's bodies and their subsequent diagnoses of heart disease in women, the researcher examined men's reports of their gynaecological functions. Charles Wood (1981) researched the medical history of women's menstruation and referred to the medieval misogyny, which imbued this knowledge. He commented that the history of menstruation had been overlooked because it was considered a normal female function. He highlighted some medieval beliefs related to menstruation. It was thought that children were more likely to be conceived when sexual union takes place one week after the end of a period so that the semen would properly form the menses from the first moment of their appearance in the womb. Women's menses were believed to accumulate in the womb, giving rise to increased sexual desire. Women were thought to be at the peak of their sexual desire when pregnant. This is an explanation of men's fear and ignorance of women's bodies prevalent in medieval thought and writings.

As shown in figure 3.3, men's ignorance about women's bodies was illustrated as fact even if it was fiction. The woman's head is covered signifying her modesty and respectable position in society as the bearer of children. The uterus above her head shows the position of the foetus in utero and immediately prior to delivery.

This medical illustration shows the portrait of the Disease Woman with a heart placed in the chest area the same as a man's but the uterus is located near to the hip. It is obvious to women that a man has drawn the picture, as any woman just has to feel the presence of her uterus though bodily symptoms in the abdominal area. Just as a man can feel the location of his heart by its rhythm or his testes when they contract due to the cold.

Figure 3.3: The Medieval Medical Miniature is called the Disease Woman, is depicting the heart in the correct place and the uterus is located near the hip instead of in the centre of the pelvic area (Jones, 1998, p. 34)



### ***Women's roles in the healing profession***

The role of women in medicine or as they were termed 'wise women' appeared in English manuscripts in the 15<sup>th</sup> century. They were described as healers. They were usually well-born ladies who diagnosed and prescribed remedies to treat ailments for people in their households. The lack of pictures to support women's roles as healers is misleading, as it does not represent the scale of women's activities as having a leading role in treating illnesses mostly without the help of books. Wise women had medical roles in terms of pregnancy and midwifery. In Naples, women were officially recognised and permitted to practise surgery and gynaecology after passing an examination by royal physicians and surgeons. Dame Trotula of Salerno in the 12<sup>th</sup> century (Jones, 1998) has been attributed authorship of passages on obstetrics during the Middle Ages. She was considered to be the 'Empress of Midwives' and

she has been pictured holding an orb in the left hand signifying her status (Jones, 1998). An illustration shows that women had significant medical roles, which were largely ignored in medical texts. The picture (Figure 3.4) shows us a woman surgeon conducting a caesarean section to assist the delivery of a child.

Figure 3.4: A Miniature from a fourteenth-century "Historie Ancienne." (Jones, 1998)  
A female surgeon performing a caesarean section to deliver a baby



Initially caesareans were performed only on women who had died, in an attempt to save the baby. Later on they were performed on living women, who more commonly died from infection. Currently a death from caesarean is relatively rare because of sterile practices and antibiotics.

Male medical views were perpetuated because women healers were not perceived as making a significant contribution to scientific matters throughout history. Male publications regarding women's anatomy and their physical functions were coloured

with misogynistic attitudes that have remained throughout history up to the present day. When autopsy became an acceptable practice for extending medical knowledge, traditional male views dominated the autopsy analysis. 'Der anatom', a picture by Gabriel Von Max (Bronfen, 1992) encompassed two interests. These interests were, firstly, the study of positivistic anthropology and material nature and secondly, a fascination with spiritualism (Bronfen, 1992). A prevailing belief at the time, was that a woman's dead body when dissected, allowed her body's interior to be visible so that theories of female sexuality could be verified. The dead woman's breast is exposed to the anatomists' gaze and closely adjacent to his hand, while her genitals are veiled and thus absent from view. The female corpse is passive, at the disposal of the anatomists gaze. His upright posture signals control and domination. The anatomist is portrayed as surviving, interpreting the woman's bodily signs and recording his knowledge in writing, about the woman with attendant male authority. This picture intimates that the survivor is able to translate the ephemeral object (a woman's body) which is observed with a male gaze into stable signs, that carry a male signature (Bronfen, 1992).

### **Superstitious beliefs impeded attempts at heart surgery**

Before the 19<sup>th</sup> century, Physicians regarded the heart as the seat of the soul. Aristotle had stated that the heart of all the viscera cannot withstand injury. Galen considered that injuries to the heart were fatal and for the times it was probably true. Early in the 19th century Bell considered that heart wounds were always fatal and it was not useful to discuss the subject. Masculine activities such as fighting in wars caused heart wounds. Larrey, Napoleon's surgeon, questioned this view and drained the pericardium of a soldier who had developed tamponade after stabbing himself. Bloch sutured heart wounds in rabbits in 1882. In the same era, Billroth (a purportedly enlightened surgeon) and Riedinger were disparaging and skeptical about this type of heart surgery because they were influenced by the prevailing beliefs at that time. Billroth was reported to have stated surgeons deserve to lose their colleagues' esteem if they operated on the heart (Johnson, 1970). There has been considerable controversy in the literature as to whether he made this statement. Riedinger's notes showed that this topic (heart surgery) scarcely deserved a mention. Cappelen in Norway 1896 attempted the first suture of the human heart; the injury was caused by a stab wound (Johnson, 1970).

### **How stereotypes influence medical practice**

In 1910, Osler gave a paper on Angina Pectoris to the Royal College of Physicians of London. Heart disease was perceived as a man's disease. He linked the physical state of arteriosclerosis with feelings, emotions and behaviour. He reported three causes of angina, "sudden muscular effort", "mental emotion is a second very potent cause", the third factor is "flatulent distention of the stomach" and "another common exciting cause is cold" (Osler, 1967, p. 333). He described the type of person who would be more likely to experience angina. His description reinforces male images of heart disease by using military images of male prowess.

It is not the delicate neurotic person who is prone to angina, but the robust, the vigorous in mind and body, the keen ambitious man, the indicator of whose engines is always at 'full speed ahead'. There is, indeed a frame and facies at once suggestive of angina- the well 'set' man of from 45 to 55 years of age, with military bearing, iron-grey hair, and florid complexion. More than once has such a man entered my consulting-room and the suggested diagnosis of angina has flashed through my mind (Osler, 1910, p. 839).

Osler's description of the heart and circulation is that of a pump and pipes. He uses a masculine example of the heart function that of an engine controlled by men to maintain the heart in a state of equilibrium.

The circulation as a whole may be compared to a vast irrigation system.....The engine pumping steadily night and day keeps a steady uniform supply in the mains (Osler, 1910, p. 840).

Osler (1910) discussed cases of angina caused by emotional influences after family members had died from angina attacks. A brother and sister (aged 28 years and 38 years respectively) presented with severe chest pain after their father's death. These patients became well again after medical reassurance that their symptoms were not cardiac in origin. He also referred to emotional influences that caused an outbreak of angina attacks in sailors of the French corvette L'Embuscade. Osler suggested that

women were more likely to suffer from chest pain brought about by emotional distress.

The cases of neurotic angina pectoris in women call for the greatest care in diagnosis (Osler, 1967, p. 839)

Similarly, forty-five years ago Friedman and Rosenman (1959) formulated the Type A behaviour pattern that was presumed to be associated with, or induced, changes in serum cholesterol and blood clotting time. Eighty-three men (Group A) were selected because they manifested:

a sustained drive for achievement and as being continually involved in competition and deadlines and in their avocations (Friedman & Rosenman, 1959, p. 1286).

These men were compared with 83 men (Group B) who had the opposite behaviour pattern and 46 men (Group C) who were unemployed visually impaired and manifested a chronic state of insecurity and anxiety. Coronary artery disease was seven times more frequent in Group A than Group B or Group C. Factors other than the Type A behaviour pattern were analysed and the behaviour pattern was held to be responsible for the group differences. Most participants were not observed to have severe neurosis. These researchers attributed the behaviour pattern as striving to attain a higher status (Friedman & Rosenman, 1959) in Western society. This variety of stressors was perceived as never previously seen throughout history. However, Osler's (1910) case histories show people were experiencing severe stress in life events or in dangerous occupational situations. Nevertheless, both researchers' findings were based mainly on men.

## **Part Two: Gender and Culture**

This section discusses the socially constructed concepts of gender and culture. The first part defines gender, and discusses cultural constructions of gender, stereotypes and their influence on decisions to seek care for heart symptoms. The second part defines culture comparing egocentric and sociocentric cultures. The influence of

cultural factors on health behaviours is explained together with a discussion of individual and collective cultural factors.

## **Gender**

In order to discuss gender differences among the study participants it is necessary to consider this concept as it is reported in the literature. Gender is literally defined as the:

Grammatical classification of objects roughly corresponding to the two sexes and sexlessness (masculine, feminine, neuter, common) (Fowler & Fowler, 1962, p. 410)

This simple articulation of gender does not begin to capture its complex meaning that continues to evolve over time. In the next section two different perspectives regarding gender will be discussed and compared.

## **Cultural constructions of gender**

The following comparison demonstrates differences in perceptions regarding gendered roles. Hofstede (as cited in Robbins, 1991) surveyed 160,000 employees in sixty countries where he found variations in national cultures. He found four dimensions of national culture: individualism vs. collectivism, power distance, uncertainty avoidance and masculinity versus femininity. Only the dimensions of masculinity and femininity are used for this comparison. Hofstede (1998) describes femininity and masculinity as two facets of the cultural construction of gender in studies of national cultures. Femininity means a society where men and women are both supposed to be modest and tender and concerned with quality of life. Masculinity refers to a society where men are assertive, tough and focused on material success and women are supposed to be more modest, tender and concerned with quality of life. Hofstede argues that gender roles in a child's family affect values relating to what is considered appropriate for girls and boys, but does not determine gender differences in wider society.

Hofstede states that it is only those women who are outstanding in their professional lives, and are in the upper socioeconomic classes who can delegate their household

and child rearing responsibilities and have public roles outside home. His studies have included New Zealand populations who were perceived as a masculine culture, where children are controlled by their parent's examples, where mothers and fathers roles are not equal and where women deal with feelings and men deal with facts (as cited in Robbins, 1991). The values of caring and gentleness are usually ascribed to women. Women are more frequently found in occupations that require a caring and nurturing role (such as nursing, school teaching or secretarial work) (Hofstede, 1998). Hofstede (as cited in Robbins, 1991) applies stereotypical roles to women and men which confines each sex within strict boundaries of behaviour.

Chodrow (1995; 2002) takes a different view in that gender is a personal as well as a cultural construction. She views gender identity as a fusion of personal and cultural meaning where there are many masculinities and femininities. She supports the view of contemporary feminist theorists, where gender is not seen as one universal defining characteristic. Gender is perceived as being rooted in language, culture and discourse influenced by Foucault and other postmodernist thinkers. Feminists recognise differences as political and social issues created by power inequalities. She states that feminist theory has taken culture as an imposed category over individual meaning.

Chodrow used recent case studies of white, middle class, heterosexual American women to demonstrate that the "gendered self" (Chodrow, 2002, p. 245) has individual and idiosyncratic parts within gender constructions. Chodrow's therapeutic sessions with these women raised some important points about gendered experiences. She introduced the elements of a psychoanalytic encounter into the concept of gender. Those elements are the transference, projection and introjection that occur in a therapeutic encounter between the therapist and the client, for example, when angry feelings about a client's situation may be projected on to the therapist, or vice versa. These elements can occur within interactions between two people in daily life. Chodrow's work challenges feminist assumptions about gender as solely a cultural or political construction. Her premise is that feminism has ignored personal, emotional meaning, or made it second place to the construct of language and power dynamics. This standpoint places gender as a construction in a wider sense to capture the individual meanings that gender has for each subject.

Gender meanings as feminism has argued, are certainly indeterminate and contested, but they are indeterminate and contested not only culturally and politically but also as they are shaped and reshaped by an emotional self (Chodrow, 2002, p. 240).

Chodrow states, “perception and construction of meaning are psychologically constituted” (Chodrow, 2002, p. 239) through emotional and fantasy experiences related to the person’s social context. These constructs undergo a continual process of re-evaluation and formation throughout life.

### **Gender stereotypes and care seeking for heart disease**

Gender differences in treatment delay have been previously mentioned in Chapter Two, where lay interpretations of symptoms were seen to reveal decision rules such as the “stress illness rule”. This rule occurs when people attribute their symptoms to stress rather than physical illness. Gender stereotypes influence how people interpret and give meaning to their cardiac symptoms.

Martin and colleagues (2003) found that stereotypes influencing beliefs about heart disease symptoms used gender as a decision rule. For example, when cardiac symptoms are experienced, such as chest pain or shortness of breath, the symptoms are more likely to be attributed to angina or a heart attack in men rather than in women. They suggested that two factors affecting people’s judgement were availability and representativeness. Availability occurs when an individual experiencing symptoms can recall a similar event. Women and men receive different exposure to cardiac events. For example, men may have more experience with male friends who have experienced angina or a heart attack. Women might be less likely to have female friends who have experienced cardiac symptoms. Representativeness refers to the classification of an acute event by comparing it to personal illness experiences. Lay people would be more likely to believe that men were experiencing a heart attack and would summon emergency services. Using the gender rule would mean that spouses, extended family, or others in the social network would offer advice based on male stereotypes of heart disease. These investigators tested gender stereotypes in a series of study populations mainly comprised of Europeans who were young university undergraduates and physicians. Their findings showed that men

with consistent symptom attributions sought treatment, while women with inconsistent symptom attributions were uncertain about treatment seeking. This model is too simplistic because it is based on the assumption that women's symptom experiences are the same as men's. This model does not take into account common and uncommon cardiac symptoms as described in the medical literature (Martin & Suls, 2003). Therefore it has limited application until more is known about women's typical and atypical symptom presentations.

## **Culture**

This section discusses culture. Culture is defined and discussed in terms of constructions of cultures and the influence of cultural factors on health behaviour. Research on cultural factors and cultural health beliefs is outlined. Individual and collective cultural beliefs are explained and related to studies of cultural factors and illness representations. Finally there is an explanation of Maori rights and Maori identity as the indigenous people of New Zealand.

### **Defining culture**

The concept of culture can be explained as a shared system of understanding. Culture influences health seeking and health protective behaviour. Health and sickness are culturally relative concepts where health practices and health services have culturally specific forms (Helman, 1994). This definition encompasses shared meaning between different groups that applies to the way women and ethnic minorities understand the world. But these definitions fail to take into account the diverse range of perceptions, opinions and responses to situations within socially constructed roles.

### **Constructions of culture**

Helman (1994) takes the same stance as Chodrow (2002) where culture has been misunderstood through the use of stereotypes linked to particular ethnic groups, such as: portraying all people of Maori descent as poverty stricken. Such generalisations about people's beliefs or behaviours do not take into account individual factors such as age, gender, intelligence, and appearance, etc. Another aspect of broad generalisations about culture is that it can lead to stereotypes through cultural misunderstandings driven by prejudices or discrimination. A misuse of culture in medical care settings may be that it is used to over interpret how some people present

their symptoms to health professionals (Helman, 1994). Helman argues that rich, poor, powerless or powerful men and women all have distinctive cultures with different norms and expectations within society. Therefore gender and culture are complex social constructions that impacts on the way people seek health care.

### **Cultural factors influence health behaviour**

Cultural variables are handed down through generations by socialisation and contribute to care seeking behaviours. Acculturation usually refers to the learning of another culture different from one's primary or first culture where people incorporate some aspects of a bigger society (Helman, 1994). Landrine and Klonoff (2001) state that health researchers never focus on the independent cultural variables that contribute to health behaviour. In their view, which is supported by Leventhal and colleagues (H. Leventhal et al., 1997), culture is not addressed or confronted in psychology and this situation leads to assumptions that ethnic populations are not different to westernised society.

Ciofu Bauman (2003) describes culture as a dynamic process with a communication system based on shared beliefs, values, customs, languages and behaviour. Researchers have found that there are differences in illness beliefs between egocentric cultures and sociocentric cultures. Egocentric cultures, comprised mainly of white Europeans, adhere to a biomedical model of illness where mind and body are perceived as separate entities. Sociocentric cultures do not separate mind-body connections and embrace religious, medical, spiritual, emotional and social processes. Landrine and Klonoff (2001) compared seven sociocentric groups and found similarities in beliefs about illness folk disorders, and folk healers. For example, these groups (Latino, African American and Native American) viewed illness as a result of "imbalance and disharmony that arises out of relationship conflicts, behavioural and moral transgression and negative emotions" (Ciofu Baumann, 2003, p. 243). This worldview of health and illness incorporates physical, psychological, social, spiritual and moral levels. These two different worldviews of health and illness (egocentric and sociocentric) can lead to misinterpretation of health behaviours across groups with different cultural backgrounds (Landrine & Klonoff, 2001).

Self-regulation models (H. Leventhal et al., 1997) assume that the individual is a problem solver actively making decisions in response to symptoms and evaluating how to achieve the best outcome. An example of this is a person taking Panadol to relieve the painful symptoms of a headache. People use their past experience of symptoms, compare their pain experiences with other similar events in their social milieu or seek reassurance about symptoms from significant others. Symptom perceptions that are shaped by cultural values and individual symptom experiences are closely bound together and they are the link that binds body and mind. Cognitive processes are filtered through the normative beliefs that differ between women and men within each cultural framework (Ciofu Baumann, 2003; H. Leventhal et al., 1997).

### **Cultural influences on interpretations of health knowledge**

Kleinman and colleagues (1995) using discourse or illness stories have done the most significant work, in the researcher's view, in understanding cultural interpretations of health knowledge. The explanatory model explains how people understand their illness experiences by interpreting somatic, psychological and social experiences within their particular cultural system. Ciofu Bauman supports the significance of this model and states that: "reflect social class, cultural beliefs, religious beliefs and past experiences with illness" (Ciofu Baumann, 2003, p. 244). This model explains the lay person's perspective and begins with an awareness of bodily sensations and symptoms. The questions used to elicit this information are as follows:

1. What do you think caused your problem?
2. Why do you think it started when it did?
3. What do you think your sickness does to you?
4. How does it work?
5. How severe is your sickness?
6. Will it have a short or long course?
7. What kind of treatment do you think you should receive?
8. What are the most important results you hope to receive from this treatment?
9. What are the chief problems your sickness has caused you?
10. What do you most fear about your sickness? (Kleinman et al., 1995, p. 256)

Patcher (1994) and Kelly (1999) are researchers who have investigated different cultural groups and settings. They have used the above framework. More recently, researchers have used the self-regulatory model to examine illness representations focussing on quantitative methodology rather than qualitative techniques. Quantitative methods provide predictive models using individual beliefs and behaviours. Ciofu Bauman (2003) considers that one of the strengths of the explanatory model is that it can increase the understanding of cultural influences on illness beliefs and behaviours. This author notes that some cultural groups have not been widely studied, for example the Latino groups mentioned by Landrine and Klonoff, (2001) which supports the researcher's stance because there is a paucity of information in the literature about cultural groups and illness representations (Ciofu Baumann, 2003).

### **Cultural groups can share common illness beliefs**

Previous research (Landrine & Klonoff, 2001) on illness representations has been conducted with cultures that share common languages, traditions and have similar socio-political environments. Latino cultures from Latin America and the Caribbean share common beliefs about the hot/cold theory of disease. An example of this theory is that diarrhoea is a hot condition and is relieved by treating it with cold foods such as honey or dairy products.

Ciofu Baumann states (2003) culturally constructed beliefs about illness can be shared across cultures. The illness representation is defined within a cultural context, has a specific label for symptoms, an expected cause for the illness, an anticipated outcome, a timeline and ways of controlling the illness. The most significant example used to demonstrate shared illness beliefs across cultures was Kay's (1993) investigation of fallen fontanelle. The physical manifestation of fallen fontanelle is described, as "The fontanelle that falls can be one of several spaces covered by membrane between the bones of a fetal or young skull" (Kay, 1993, p. 138). The fontanelle can be felt as a soft spot when compared to the rest of the skull. It closes over at approximately 9 to 12 months of age. The Latin terminology for soft spot is mollis (soft). The Mexican and American Mexican label for this condition is mollera caida. The depressed fontanelle is used in contemporary medicine as a sign of dehydration, most commonly caused by diarrhoea.

Kay traced beliefs about 'fallen fontanelle' from written records in European history through to contemporary reports using examples of this condition from Africa and Asia. Kay's work provided a unique validation of the researcher's investigation of historical beliefs about the heart. Kay commenced her work with the point of view that "no medical culture would ignore so obvious a sign of serious illness as a depressed fontanelle in an infant" (Kay, 1993, p. 140). Her interpretation included the differences between health professionals' and mothers' perceptions or interpretations of this phenomenon during infancy, and shifts in beliefs over time. The researcher had a similar point of view about tracing the origins of heart beliefs. The findings from the literature review showed the historical changes in beliefs about the heart. However, the researcher's objective differed from Kay's objective. Where Kay was attempting to find common beliefs that spanned cultures, the researcher was concerned with differences in beliefs through different constructions of gendered experiences and cultural knowledge.

Kay's work was important because it showed that the beliefs that spanned Latino cultures about 'fallen fontanelle' had common origins. These beliefs were handed down from Catholic European religious values that passed through to Mesoamerican populations from the Spanish conquest of Mexico and California. "Prior to contact with Western medical theory" (Kay, 1993, p. 141) records of Mesoamerican beliefs about the head and the fontanelle were different; they showed that 'tonalli' was a concept that included the soul, vital spirits and destiny. Kay notes that this was similar to Galen's beliefs about the vital spirits or animus where the spirits were connected from the heart to the brain. Mesoamericans believed that the head was a container for spiritual forces protected by the hair. Consequently, this culture possessed healers of the fontanelle, or Tapahtiani who conducted their cures by hanging children upside down, shaking their heads, applying pressure to the child's palate or rubbing it with salt. The beliefs about fallen fontanelle from Hispanic heritage have merged with Mesoamerican beliefs into one cultural theory. Kay attributes the reasons for this as acculturation into a dominant culture or simply because older remedies were not found to be as effective. This work has shown that different cultures can have different constructions of illness representations. Also that there are some similarities between beliefs, and that beliefs can merge together over

time through acculturation. It is important to note that Kay traced these beliefs through one strand, the Spanish-Latino connection that colonised Mesoamerica. In contrast, the Maori population in New Zealand has not been researched in this way. Therefore, it is difficult to make specific comparisons between Kay's work and the study findings. Comparison of both beliefs about fallen fontanelle and the heart demonstrates that there has been surprisingly little research on how beliefs about symptoms are formed throughout civilisation, or what influences affect changes to beliefs over time.

Research about illness representations in Maori and Pacific populations is still in its infancy. Contemporary Maori beliefs about illness have been established by the writings of Durie (Abbott & Durie, 1987; M. Durie, 2001; M. H. Durie, 1977, 1985). As previously mentioned, Petrie and colleagues (H. Leventhal et al., 1997) argue that illness representations are monocultural which contradicts Kleinman's (1995) work, Ciofu Baumann's (2003) analysis, Kay's (1993) interpretations of fallen fontanelle, and the researcher's findings. To date, research about Maori illness beliefs has not been specifically linked to psychological research using the self-regulatory model of illness representations (H. Leventhal et al., 1997).

### **Difficulties separating individual and cultural representations**

Previous research by Garro (1988) examined individual and cultural perceptions of high blood pressure. Garro's review found that

Although no sharp distinction between an individual's model and a cultural model can be made, researchers have generally focused on one or the other, and the relationship between the two remains relatively unstudied. (Garro, 1988, p. 98)

This study examined variation and consensus in knowledge about high blood pressure. Participants provided one cause for their high blood pressure and then gave other probable causes, as the illness was perceived as episodic with several causes each relating to a different episode. An analysis of true-false questions provided support for a cultural model of knowledge for high blood pressure that was shared by this Ojibway Indian community. There were 26 study participants and 69% believed

that high blood pressure was caused by too much worry. There were three main areas of individual variation in illness beliefs from the consensus mode. These were: participants believed that high blood pressure was hereditary, attributed their symptoms such as headaches to high blood pressure instead of other illnesses and some beliefs were idiosyncratic (Garro, 1988). Ciofu Baumann (2003) noted in Garro's article that the boundaries were blurred between individual and cultural models of illness. To illustrate the point she used the abovementioned quote from Garro but left off the ending, which reported that the relationship had not been widely studied. When researchers choose to omit information from the study text in this fashion it creates the illusion that their own article is the correct version. When, in fact, individual and cultural representations have not received much attention from researchers. Garro's (1988) research provided a small snapshot into cultural models of illness it was not statistically significant, and therefore was not a definitive answer in itself.

Ciofu Baumann (2003) argues that an individual's symptom experience may differ from generally accepted cultural models of illness, and that the individual resolves the discrepancy by viewing their condition and accompanying symptoms as exceptional. This author used Meyer and associates (1985) example where an individual who reported that their high blood pressure was symptomatic but stated that other people would have symptoms. The findings supported Baumann's perspective and showed that the longer that participants had been treated for hypertension there was a greater likelihood of monitoring and reporting symptoms.

These researchers (Meyer et al., 1985) reported that 64% of the participants had requested that their ideas not be communicated to the doctors treating them. This point is vital for three reasons. First of all, it brings to light unacknowledged information about the dynamics of patient-practitioner interactions. Secondly, it suggests that lay people have anxieties about communicating the expected consequences of their illness beliefs to health professionals, who are perceived as the experts. Thirdly, in a subtle way, this comment hints at socially accepted rules for communicating the presence of distressing symptoms within the patient-practitioner relationship (Argyle & Henderson, 1985). Reporting participant's reluctance to share information with health professionals makes the power dynamics within the

researcher-researched relationship quite transparent. The participants were researched to elicit information for experts to report in scientific articles, but in this case the participants' anxieties about the research process were noted in the article (Oakley, 1981).

### **Do cultural factors influence illness representations?**

Evidence that culture specifically influences illness representations has been provided by several studies (Farmer, 1994; Kay, 1993; Kleinman et al., 1995). Cultural influences create rich and complex interpretations of disease characteristics permeated with personal illness experiences and a heritage of cultural perceptions about particular illnesses or health practices. Ciofu Baumann (2003) used the symbolism of American Indian and indigenous Alaskan cultures where a sacred tree is the symbol that represents life and positive energy. The sacred tree represents the universe, life, cycles of time, protection, nourishment, wholeness, growth and health. These cultural worldviews are not sustained solely by facts and objectivity, but are perpetuated through evolving practices within cultural groups. People from other cultures may not understand illness representations that are imbued with the symbolism and imagery of a particular culture. Ciofu Baumann suggests that factual health information may be less influential for cultural groups than messages that contain cultural symbols and understandings.

Ciofu Baumann (2003) suggests that less developed cultures do not recognise affective distress and somatic experiences that are attributed to illness and incorporated into illness representations. Kay (1993), Kleinman (1995) and Farmer (Farmer, 1994) have taken a very thorough approach to identifying the source and evaluation of health beliefs from the beginning of recorded beliefs to contemporary times. Farmer (1994) described the development of an illness representation of autoimmune deficiency syndrome (AIDS) in Haitian culture, over five years that grew from contact with individuals suffering from the disease. The perceived cause of AIDS changed from being attributed to a natural cause (e.g. God's illness) to a concept that the disease was caused by a germ whose symptoms were skin sores, 'drying up' and diarrhoea. Beliefs evolve and can change according to the nature of symptoms, procedures that fail to relieve them, or new procedures can be learned to cope with symptoms. These evolving procedures can work alongside the westernised

social construction of illness as they incorporate what is known about two cultures and move forward together in contemporary knowledge and time.

### **Maori health rights in terms of the Treaty of Waitangi**

Maori cultural identity influences their care seeking behaviour for illnesses. In 1840, the cultural identity and the rights of Maori have been written down in a treaty document. The position and rights of Maori as indigenous people is established in the Treaty of Waitangi signed in 1840 by representatives of the British Crown and Maori chiefs. Since 1985, the Standing Committee on Maori health has used the Treaty as the basis for good health. The current Labour government recognises that Maori have defined rights under the terms of the Treaty of Waitangi that give Maori as tangata whenua (local people) a different status from other citizens in New Zealand (Aotearoa) (New Zealand Ministry of Health, 2000). The treaty document is phrased in broad terms (M. Durie, 1994), and contained three articles. These articles related transfer of sovereignty (Article One), the continuation of property rights (Article Two), and citizenship rights (Article Three). The recognition of Maori health rights is now an integral part of health policy and health legislation (M. Durie, 1994). An application of Treaty principles as a framework to address Maori health is:

- **Protection:** Article One – Kawanatanga – the right to participate or have self-determination to protect the interests of Maori.
- **Partnership:** Article Two – Tino Rangatiratanga – the right to share ownership of resources. The responsibility for non-Maori to maintain partnership with Maori.
- **Participation:** Article Three – Oritetanga – the right to participate in government structures and process that improve the health of Maori (M. Durie, 1994).

All health researchers in New Zealand are required to understand, and be able to work in ways, that recognise the Treaty of Waitangi. Partnership with Maori in research initiatives is consistent with government policy and legislation.

### **Defining Maori cultural identity**

The Maori renaissance of language and cultural heritage demonstrates a contemporary approach to the role played by identity within cultural groups. Durie (1999) states

that Maori mental health problems stem from insecure Maori identity. A lack of integration with whanau, culture and society and within the self leads to self-fragmented and self-centred behaviour. This behaviour results in an absence of purpose or responsibility. Mason Durie argues that within indigenous cultures, there is a shared DNA pattern and shared attributes but there are no specific single set of mental or emotional constructs that makes up a typical Maori identity (M. Durie, 2001). Maori diversity is made up of eight variables:

- Demographic, where a young population will increasingly age,
- Geographic spread across urban, rural and overseas locations
- Gender (Male and female), where females are disadvantaged
- Living standards, where disparities are growing within living standards, health status, incomes, employment and educational achievement
- Lifestyles, where there is increased drug and alcohol use and high achievement in sporting activities
- Language, where there is greater use of Maori language (Te Reo Maori) but fewer native speakers
- Affiliations with multiple affiliations to tribal groups, community links and involvement in politics
- Whanau, where there are reduced linkages and quality of involvement among families

Measurement of Maori identity is determined by self-identification (ethnic and tribal affiliation), access to cultural resources (skills and knowledge in Maori language and customs), access to Maori physical resources (land, fisheries, wahi tapu and tribal estates), access to Maori social resources (whanau, friends, educational institutions, Maori and tribal services). According to Durie, these internal and external characteristics of Maori identity go beyond cultural affiliation, knowledge and behaviour to include access to resources of the group. Durie's (2001) rationale is that cultural identity is an abstract perception of belonging to a cultural group. Durie states that cultural identity has little meaning if the cultural, social and economic resources of the group are not readily accessed.

Maori health before 1800 was based on communal living and a close relationship between people and the natural environment. Maori public health was based on

values that used the concepts of tapu (risky or sacred) and noa (safe or profane), for community regulation and control. During certain times, areas of land, water or bush required protection using tapu laws. An adequate source of food supply was maintained by the exercising of a rahui (a tapu to place certain foods off limits). Rahui acted as a conservation measure to increase food supply for the wellbeing of the tribe. These systems were designed for the wellbeing of Maori families that used the natural environment for food and shelter and identity. Tribes would identify with a distinctive mountain or river to consolidate their ancestral heritage (M. Durie, 1994). Durie (1999) states that the standing of a tribe depends on the visible presence of respected elders. In Maori society, older people carry the status and integrity of their people. Roles for Kaumatua or Kuia include speaking on behalf of the tribe, and carrying on traditional culture, as well as protecting or nurturing younger adults and children. Older Maori are expected to demonstrate spiritual leadership and authority in Maori society.

Shared social experiences and cultural values shape contents of emotional representations. Such a variety of representations present many challenges for researchers. Partnership with Maori in this study has involved extensive consultation and collaboration to ensure that the research meets legal and statutory obligations under the Treaty of Waitangi. Investigators need to move away from the positivist standpoint where one opinion is perceived as right. Why not use strengths from both cultures and acknowledge both worldviews? This approach is outlined in terms of the Treaty of Waitangi where Maori have partnership with non-Maori in terms of health research initiatives. Academics continue to come back to designing individual interventions using a positivist perspective, with a western focus that is transferred to other cultural groups.

There has been little mention of women in historical medical reports about heart disease. What has been covered is other related literature from historical sources, medieval illustrations and literary texts. A few studies have begun to examine more closely women's heart attack symptoms comparing them in the prodromal period and at the time of hospital admission for the acute symptoms of a heart attack. Researchers have only just begun to compare women's common and uncommon heart attack symptoms compared to men's more traditional symptom presentations.

Recent research on psychological factors has covered people's perceptions and expectations about heart attacks using the self-regulatory model of illness representations. A few qualitative studies have examined women's perceptions about heart attacks and linked them to factors in the social context such as the competing demands that influence women's decisions to seek care at the time of experiencing acute symptoms. There was limited information about constructions of gender and culture but the relevant literature has been discussed and related to gender stereotypes and cultural factors in health beliefs. There has been scant research on gender differences and cultural factors that affect individual decision making processes, which was the justification for conducting this study.

## **Summary**

This chapter has contributed to the theory development of the study findings. Part One has drawn together literature from literary, mythology, scientific and medical sources to create a historic background of beliefs about the heart that includes women. By pursuing the deeper or unconscious meanings people hold about the heart, it is possible to gain further insight into the ways people behave, and what beliefs drive their daily struggle to survive. Tracing the legacy of beliefs about the heart shows how entrenched they are in contemporary society, lodged deep into our subconscious where we overlook their influence on our daily actions. In Part Two, these meanings have been linked to the constructs of gender and culture that have often been overlooked in relation to psychological reasons for delays in care seeking for heart attacks (Chodrow, 1995]; 2002; Hofstede, 1998). Hofstede's (1998) and Chodrow's (2002) perspectives on gender were compared. The studies (Martin & Suls, 2003) have limited application because they assume that cardiac symptom presentations can be based on traditional heart attack medical protocols and classic heart attack symptoms. Maori cultural identity and studies of cultural illness beliefs and the influence of culture on illness representations has been covered. The researcher's questions about the place of women in the history of heart disease has shown that women have traditionally been disregarded in philosophical and medical debates about the heart. This review informs the four results chapters, which contain the study findings.

## CHAPTER IV: GROUNDED THEORY RATIONALE

*I am a woman on a bridge, balanced between past and future across a chasm of radical change.*

Judith Evans (*Quotable New Zealand women*, 1994)

### Overview

This chapter addresses the underlying assumptions and rationale underpinning the grounded theory methodology used for this study. The characteristics of qualitative research are introduced with the identification of the theoretical perspectives relevant to the researcher's assumptions. Grounded theory is defined as a research method. Some attention has been paid to the rationale behind the interview questions, interview process and theory. The theoretical sampling technique and analysis, the sample profile and reasons for obtaining a Maori sample have been explained. Finally, the data analysis is discussed in relation to the theoretical basis of creating categories and techniques for raising them to a level of more abstract concepts for theory generation.

### **Introduction: Theoretical perspectives**

Qualitative research is an interpretive, naturalistic, inquiry process. Qualitative researchers study things in their natural surroundings and attempt to make sense of phenomena by interpreting the meanings people have about their social experiences. This methodology is conducted in the field where data is sourced, and the researcher's assumptions are acknowledged in the data collection process. Data consists of words and the outcome is the result of a process where data is analysed inductively, by focusing on participants' meanings and use of expressive language (Creswell, 1998).

Qualitative researchers approach a study with a particular set of beliefs or worldview. These assumptions relate to the nature of reality (ontology) where reality is subjective and multiple as illustrated by the participants' views that have primacy and are filtered through the professional knowledge of research methods (Popay, Rogers, & Williams, 1998). The relationship of the researcher to the topic being studied

(epistemology) is where the researcher interacts with participants to minimise the distance in the relationship. The role of values in the research (axiological) is acknowledged by the researcher and reported. Rhetorical assumptions are conveyed through terms such as understanding, discovery and meaning. The research procedures emerge as assumptions, which are conceptualised by the researcher (Creswell, 1998).

### **Grounded theory**

The central tenet of grounded theory is the development of a theory “closely related to the context of the phenomenon being studied” (Creswell, 1998, p. 56). In 1967, two sociologists Glaser and Strauss (1992) developed grounded theory where they argued that theories needed to be grounded in field data in particular the interactions, processes and outcomes affecting people (Creswell, 1998). Glaser and Strauss (1967) worked in close collaboration on a study of dying in hospitals, which led to their first publication. More recently they have differed about the application of this research method. Glaser favours starting the data collection in a pure way so that there is no recourse to the literature and the theory emerges from the data. Strauss and Corbin (1990) prefer a more structured approach with set steps in the analysis phase. Glaser has criticised the more structured approach stating that there are issues with researchers in the analysis phase where the data is forced into shape too soon instead of allowing the data to flow into an emerging theory. The logic behind development of theoretical sensitivity from Glaser’s (1992, p. 4; 1967) point of view is covered in the following two questions:

- What is the chief concern or problem of the people in the substantive area?
- What accounts for the most variation in processing the problem?

Glaser (1992) states that researchers should not ask the two questions but constantly compare the data over time to allow the theory to emerge from the data. He defines the grounded theory approach as a general methodology and a construct oriented process that uses systematic methods to generate theory.

The term grounded means that a theory must be developed from the field data and not from a predetermined hypothesis (M. Murray & Chamberlain, 1999). This process means that the researcher moves from describing and classifying events to formulating an abstract theory of the phenomenon. To describe grounded theory as an inductive method is to oversimplify the research processes. The researcher decided that Creswell's (1998) structured approach (similar to Strauss and Corbin (1990)) with data analysis was easier to follow because it was clearly set out. It allowed the researcher to develop a template on the NUD\*IST computer software programme. This template provided a comprehensive diagram to visualise the data set while creating categories inductively. This process contains the inductive component used by Glaser (1967) with regard to the way categories and theory is developed. It is driven by the researcher's assumptions about the multiple meanings in the data. During the analysis the researcher seeks an understanding of what is going on and how the data is ordered. As the analysis proceeds the theory is tested both inductively and deductively through further data collection (M. Murray & Chamberlain, 1999).

### **Feminism**

Grounded theory has its roots in the postmodernism perspective which claims that knowledge is set within contemporary worldviews and in multiple perspectives of gender and ethnicities (Creswell, 1998). The aim is to deconstruct texts to discover concealed dominations, hierarchies, contradictions and inconsistencies. Feminist research has used postmodern critical analysis to challenge gender domination in patriarchal society. There are numerous epistemological and methodological standpoints for feminism such as feminist empiricist, post modernist or critical realist. What is commonly agreed is that gender relationships must be critically analysed by focusing on the detrimental impact of patriarchal attitudes "in both academic theory and professional practice" (Ussher, 1999, p. 99). This approach is concerned with the establishment of non-exploitative relationships to reduce the invisibility and distortion of women's experiences in order to make their social position equal (Creswell, 1998; Ussher, 1999). Feminist research assumes that traditional studies of women's lives are conducted with "androcentric biases" (Ussher, 1999, p. 99). It takes a critical approach to research, where both women and men are defined by male norms. Research using men as a 'rule of thumb' measure, is considered by feminist

researchers, as portraying any differences between women and men as “inferiorities on the part of women” (Ussher, 1999, p. 99). An example of this approach is:

The phallogentric or patriarchal nature of health research and health care has been criticised, with researchers and health professionals accused of maintaining and reinforcing gendered power structures, which negate the needs and interests of women. For example, the medicalization and subsequent pathologicalization of female reproduction has been criticized as has the categorization and treatment of women with mental health problems or with cancer. Many feminist researchers and clinicians have developed alternative methods of assessing or intervening with women’s problems as a result (Ussher, 1999, p. 100).

The researcher included a feminist standpoint in the methodology, as the study focus was on women and conducted by a woman. It was assumed that this perspective would “count women in” (Ussher, 1999, p. 103) and produce a view of women’s lives that was less distorted compared to accounts interpreted by men on studies of mainly men, such as cardiovascular trials (M. M. Ottesen et al., 1996). Strategies to include a feminist perspective within the research are discussed in the interviewing process. As the researcher’s gaze studied the text for meaning in the analysis, this process was openly discussed with supervisors and study advisors using self-awareness and self-reflexivity. Feminist research provides a platform for the voices of women’s subjective worldviews and has the flexibility to disseminate the research findings in a way that benefits women (Ussher, 1999).

### **Symbolic interaction, phenomenology, and marxism**

Charmaz (1990) applied grounded theory methodology using “symbolic interactionist perspective tempered by Marxism and phenomenology” (Charmaz, 1990, p. 1611). Symbolic interactionists view human beings as social actors, who share symbols and attribute common meanings to actions and situations, through the medium of language. Individuals label the signs and symptoms of their illness, and then interactions with other people can invalidate or reinforce the illness labels (e.g. a heart attack) that may influence the delay time. Charmaz states that the assumption of symbolic interactionists as “the indeterminacy of action rests on the human capacity

to objectify self and ascribe meanings to self like any other object” (Charmaz, 1990, p. 1161). She included phenomenology which assumes that “subjective reality may take many forms” (Charmaz, 1990, p. 1161) to study objects of consciousness and emotions to correct an “overly rationalised” (Charmaz, 1990, p. 1161) view of individuals. Symbolic interaction and phenomenology allow researchers to closely examine participants’ interpretations of actions and events. Marxism assumes that “individual psychology is both shaped and constrained by social structure” (Charmaz, 1990, p. 1161). Marxist theory brings a critical analysis of social structures linked to an individual’s subjective consciousness and choice. Charmaz’s social constructionist approach, was chosen by the researcher (who included a feminist analysis) because it offered “an open ended and flexible means of studying both fluid interactive processes and more stable social structures” (Charmaz, 1990, p. 1162).

### **Using grounded theory**

The researcher’s approach to qualitative research methodology is one of a social constructionist with a feminist perspective using grounded theory (Charmaz, 1990; Creswell, 1998; M. Murray & Chamberlain, 1999). When planning this study, the researcher believed that the interview process was the pivotal point in gathering rich meaningful information. Charmaz emphasised the interview process as a way of making the data collection process more transparent. The term social constructionist means: 1) people’s creation of taken-for-granted interactions, emotions definitions ideas and knowledge about their heart attack symptoms and self and 2) Researchers’ sociological constructions are developed by studying people’s constructions of illness (heart attack symptoms). The addition of a feminist perspective allowed the researcher to look for women’s experiences of heart disease (Charmaz, 1990; Ussher, 1999).

### **Rationale for interview questions**

The researcher believed that investigators had missed the point about patient delays. Researchers, in their search for the truth, had glossed over people’s brush with death in the objective accounts of high mortality rates for out of hospital deaths from AMI. Facing death had been sanitised, taken for granted, and death is portrayed in modern society as ultimately controllable through the auspices of ‘high tech’ medical interventions. These almost mythical beliefs have been perpetuated in popular

medical jargon. Common, hip sounding statements about deaths from heart disease occur almost nightly on television or 'reality TV shows'. Statements like 'it was an arrest but they were jump started again' or 'its another STEMI coming in', or 'it's a non Q wave AMI on the way', or 'she's crashing - get the cart', reveal just how insidious biomedical myths masquerading as 'truths' can abound in everyday life.

Historically, researchers had identified 'patient delay' as the patient's fault. (Goldberg et al., 1992; Rawles et al., 1990; Wielgosz et al., 1988). Delays in care seeking for heart attack symptoms had been subsumed to the safe level of dominant medical thinking where scientists used predict and control methodologies to identify aberrant patient behaviour when people arrived late at hospitals (Dracup et al., 1995; Herlitz, 1996; M. M. Ottesen et al., 1996). This situation originated in beliefs about westernised medicine that are widely accepted as the only correct way to deal with medical problems (Bleeker & Erdman, 1991; L. W. Kenyon et al., 1991; L. W. Kenyon, Ketterer, Gheorghiad, & Goldstein, 1992). Doctors are a powerful profession and they use medical evidence supported by epidemiological findings to promote cures for physiological conditions (Doggen et al., 1993; R. Norris, 1999). Traditional psychological involvement in the medical arena has been seen as an adjunct or extension of medical authority over people's lives (Cameron et al., 1993; Perry et al., 2001; K. J. Petrie et al., 1996; Keith J. Petrie & Weinman, 1997).

The researcher wanted to get a fresh look at the phenomenon. The questions were tools to get people involved, sharing their experiences, who had faced a brush with death. The questions were constructed carefully to capture rich, varied accounts in the participant's world while allowing the researcher to piece together a scenario. (For more details, see the section on selection of questions on page 99)

### **Theory aspects of the interview process**

Conducting interviews is an exacting discipline more in the realm of counselling encounters (Egan, 1990; Griffiths & Macdonald, 1999; Tavares, Zilberman, & el-Guebaly, 2003). Close attention and supervision of interview processes (Egan, 1990) is a requirement for professional registration. Interviewing can be a nightmare for inexperienced researchers. Difficulties that can occur during questioning in interviews are: learning to listen, being comfortable with remaining silent or saying

little, coping with emotional outbursts, and being unable to offer a personal opinion about the topic (Creswell, 1998). The grounded theory methodology (Creswell, 1998; M. Murray & Chamberlain, 1999) requires an extensive interview to allow the participants to discuss their experiences. The Maori researcher was trained in interviewing skills by the researcher. Interviewing skills built on the Maori researcher's ability to conduct bilingual interviews couched within traditionally accepted Maori protocols derived from Maori counselling models (M. Durie, 2001) and marae etiquette. Matching the ethnicity of interviewers and respondents was a strategy to produce shared cultural language and meanings. Fontana and Frey (1994) state that it is very difficult to conduct interviews cross-culturally because there are different ways of saying things and some subjects should not be spoken about at all.

Qualitative studies often use to a reflexive approach with interviewing (Kottler & Blau, 1989; Ussher, 1999). Researchers write up their strategies to promote reflection about the interview. The assumption appears to be that this process is quickly learned and easy to carry out. From the principal researcher's perspective the process of interviewing requires a long period of training and practice to learn to tease out the essence of the person and the underlying meaning in the conversations (Kottler & Blau, 1989). Creswell (1998), Charmaz (1990) and Ussher (1999) support this perspective. Charmaz (1990) makes the point that the way the interview process is conducted will impact on the quality of the data. The relationship between the interviewer and the interviewee, and the technique employed needed some definition because of differences of gender background and values. Two types of social research interviews are predominant in the literature. Firstly, the view of the interviewee as a passive object for data production when correctly handled. Secondly, the hierarchical model where the interviewer is the expert or psychoanalyst using non-directive probes during the interview process to uncover the truth (Oakley, 1981). These traditional methods have their place such as in conducting a psychosocial assessment for a heart transplant recipient.

In effect, the researcher had set up a 'study across' (Oakley, 1981) situation with regard to matching the ethnic backgrounds of the researchers. A 'study across' method (to even out social and political power issues) was chosen rather than a study up or a study down the occupational scale. For instance, a 'study down' strategy

would mean interviewing working class women who assume that the interviewer is the expert. Thus, participants would not challenge her actual knowledge or query the research findings or even be able to interpret the research jargon (Oakley, 1981). A 'study across' strategy would include the participants as a part of the research team. This strategy was done in two ways: firstly, by taking time to answer questions after the interview and secondly, providing a copy of the transcript for participants to decide what information was kept for the data collection. The majority of participants were not employed in professional occupations; they were retired, with some younger participants in professional occupations. The interviewers acknowledged that there would be a difference in knowledge of heart disease symptoms between the researchers and the participants (Campbell, 1998; Wenger, 1997).

When the subject of hearts is raised the heart symbolises emotions and feelings. For most people it carries connotations of romance and heartache. It is common for people to have experienced the death of a close relative or friend from heart disease (Sanne & Wenger, 1992). Therefore, it would seem inevitable that thoughts feelings values and emotions would be an integral part of the interview process. It was important for the interviewer to create a non-hierarchical (Sanne & Wenger, 1992) relationship thus acknowledging the balance of power that existed during the interview conversation. It was decided and written explicitly in the ethical application that participants would be offered counselling sessions if they became distressed during the interview.

### **Rationale for the interview process**

There were two women interviewers, each woman had an academic and professional background, one was European (the researcher) and the other was Maori (the interviewer). In the initial stages of this study, the researcher interviewed three senior Maori key informants to establish parameters for the Maori dimension. She also interviewed European participants. The Maori interviewer conducted the interviews with Maori participants so that there was an ethnic match between interviewers and participants. The scope and funding provisions for the study did not allow for male interviewers to conduct interviews with men participating in the study.

Grounded theorists use a different approach than most qualitative research because they are involved right from the start in shaping the data that they collect. Glaser and Strauss (1992; 1967) (See page 82 for an explanation of Grounded Theory) assume that researchers are trained and skilled in their respective fields with perspectives to observe and build analyses. Their assumption is that by using a combination of disciplinary and theoretical perspectives grounded theorists can develop new ideas and theories (Charmaz, 1990; Glaser, 1992; Glaser & Strauss, 1967). These assumptions seem to bypass the importance of specialist interview training.

When contemplating how to elicit high quality data from the interviews the researcher believed that skilled interviewing techniques could not be emphasised enough as a way of discovering useful information. The researcher's background in listening skills, counselling and experience with the difficulties of managing an interview encounter drove efforts to ensure that interviews were conducted with skill and sensitivity within standards of ethical practice for counsellors. The Maori interviewers' language and cultural skills were an additional bonus because they were a scarce resource. A significant amount of time was spent preparing for the interviews, reflecting on the process, and making efforts to change or improve interviews as the data collection progressed. The researcher believed that the researcher-respondent relationship carried particular responsibilities. The researcher ensured that both women interviewers identified themselves, their institutional affiliations, provided clear information about the interview process, were concerned about the welfare of participants, and respected the respondents' privacy, anonymity and confidentiality (Sarantakos, 1993).

The 'study across' procedure incorporates efforts to level the playing field in the interview and actively include participants in the data gathering. After reflection about the study across procedure, a central issue became apparent. It was anticipated that participants might perceive that the interviewers were experts about heart health. The researcher expected that during the interview process participants might ask questions about heart disease.

The 'study across' procedure was established by using three strategies (Oakley, 1981). The first strategy for establishing a study across encounter was the

researcher's decision to answer any questions about heart health. The researcher decided to attend to information about sources of heart health after the interview had ended. The researcher informed participants about this strategy at the beginning of the interview. For example, a participant's request for information about cholesterol, blood pressure or other risk factors was dealt with by answering simple questions about risk factors and referring them to the free brochures offered by the National Heart Foundation of New Zealand. The second strategy was to include a final open-ended question asking whether participants would like to add anything to the interview or to include anything that was important or anything not covered by the interviewers. This strategy was intended to be a check for assumptions made by the interviewers. The participants' contribution about what they thought was important in their stories was considered to be vital information not shaped by the researcher's assumptions. The third strategy was that participants understood that they would receive the interview transcript to provide feedback for the researcher. Participant's corrected or deleted any information in the transcript that they considered incorrect or inappropriate.

### **Grounded theory sampling and analysis**

This approach deliberately links theoretical sampling, data collection and analysis. Information gained from the interviews plays a major role in directing further data collection. This process provides the researcher with the opportunity to increase the density of emerging categories. It contributes to the theory development by allowing the researcher to check unexpected findings, insights, ideas, intuitions and hypotheses (Creswell, 1998).

#### *Sampling rationale*

The sampling method employed non-probability samples. The population of interest was identified through theoretical sampling, which is a purposive sampling technique. This procedure was conducted in three phases (Charmaz, 1990; Creswell, 1998). Data collection was based on constructs relevant to the theory rather than representativeness of specific populations as in probability sampling (Beaglehole, Bonita, & Kjellstrom, 1993). The first stage of theoretical sampling is called open sampling. It is designed to obtain information relevant to the research question. This data was broken open (open sampling) and initial categories were identified. A

primary concern for rigor in qualitative research is evidentiary adequacy where there has been sufficient time spent in the field to gather an extensive body of evidence (Charmaz, 1990; Creswell, 1998). In the second stage, systematic variational sampling was used to gather data that could confirm, expand and explore categories and identify category relationships. This part of the analysis is called axial coding; where new categories are identified, current categories are being refined or developed and linked together. Further variational sampling was required at this stage. The third stage is termed discriminate sampling where data is deliberately selected from persons or sites to verify the central category that binds together all other categories (Creswell, 1998).

### *Maori participants*

The decision to use Maori Health Trust rooms for the interview was based on a number of concerns.

- It is difficult to recruit sufficient numbers of Maori for research purposes because they are reluctant to seek medical care in mainstream health services based on the dominant westernised view of health.
- Maori health services established with Maori values have been a recent development. This study would not have been possible without the Maori Health Trusts and the Maori health professionals (who were the health providers). Identification of Maori patients with heart disease problems would have been very difficult.
- Health Trusts recognise tribal heritage and foster a sense of belonging for Maori.
- The local Maori Health Trust was one that the participants felt familiar with because it was where they received regular check ups for their heart disease.
- External links were already established with families because the mobile Maori nurses regularly made home visits to assess chronic conditions such as diabetes.

Maori nurses contacted the participants about the study, arranged the interview time and introduced them to the Maori interviewer. Participants commented to the Maori interviewer that if they did not keep their appointments the mobile nurse would be

around to visit them. They felt supported by the nurses to attend the interview and in some cases were transported by the clinic van.

### *Sampling saturation*

Explicit sampling is essential for theory development. It creates the opportunity for the researcher to question how important the categories are in relation to the emerging theory. As categories become more abstract some will become more important than others in theory formulation. Saturation of categories occurs when no new categories relating to the theory emerge from the data. At this stage the researcher examines the data for cases that do not fit with the theory. Data collection ceased when all categories were linked with the theory (Creswell, 1998).

### **Data analysis**

Charmaz states that the researcher's stance is "a delicate balance between possessing a grounding in the discipline and pushing it further" (Charmaz, 1990, p. 1165). Charmaz states that researchers can be immersed in their particular frame of reference such as medical sociologists who use stigma as a concept to order data and only use the concept as it is described in the literature. Grounded theorists use concepts to ask new questions by sensitising concepts related to central issues without reproducing the same static set of concepts. Social constructionists can provide a new perspective in terms of existing concepts. A social constructionist approach in the analysis perceives the analysis as an active process rather than a passive scientific set of observations (Charmaz, 1990). The interaction of the researcher with the data results in a discovery process through the creation of categories. This perspective acknowledges that the researcher has a store of values and constructions around power, status, hierarchy and self-concept. These constructions led to the questions that the researcher asked to break down the study findings. (See methodology section page 99)

Further theoretical coding raised the data from a systemised set of categories to the emerging theory. The researcher organised the data using Glaser's (1992) six Cs schema to describe the process that explained the movement from cause to consequence. Creswell's (1998) method of data analysis uses Strauss and Corbin's (1990) analytic structure of the six C's for developing hypothetical relationships

between conceptual codes in the axial coding phase. The six C's were not fully explained by Glaser (1992) so the meaning of these terms has been described in Creswell's data analysis. The researcher used Creswell's (1998) terms and dictionary definitions (Fowler & Fowler, 1962) to explain the meaning. The six C's are as follows:

- Causal conditions are what influences the central phenomenon
- Context the environment or setting where the events or behaviour occur
- Contingency of uncertain occurrence or true only under existing conditions
- Consequences the result of something that comes by causation or logical inference
- Covariances connected variables are included without pre-empting ideas about the cause (covariances can influence and change the researcher's interpretation of the main theme)
- Conditions those factors essential to the existence of the phenomenon being studied

This process shaped the researcher's thoughts about the data and provided a framework to fit the participants' individual stories together to give each experience more meaning within the analytic process than a single set of circumstances.

The initial stages of data gathering and analysis in grounded theory are usually conducted before undertaking a literature review. This strategy focuses the analysis on information derived from the field data. However, this research was based on previous pilot findings (Campbell, 1998). So the researcher had some prior understanding about the phenomena. A vital part of the analysis is that the researcher must acknowledge this influence so that the developing theory is not biased. Theoretical sensitivity is the term used for the later stages of theory development. This is the time when the researcher uses previous knowledge, refers to the literature, participants and co-researchers to interpret the findings (Creswell, 1998). "Later in the research process is a strategy to prompt exploring various ways of analysing the data" (Charmaz, 1990, p. 1163). Charmaz emphasises that it delays the literature review

until the researcher develops the first category and compares relevant publications to place the study within the literature.

## **Summary**

This chapter has covered the philosophical understanding of the social constructionist and feminist perspectives that have informed the emergent theory based on the field data. It has influenced the methodological approach used by the researcher who emphasised that the interview process is a vital ingredient in the collection of substantive, rich data. This methodological approach places the participants' experiences in terms that they understand within their particular social milieu. The philosophic traditions, ideological perspectives and the theoretical assumptions contributing to grounded theory. This chapter provides the theoretical underpinnings that inform Chapter Five, which contains an explanation of the study methodology.

## CHAPTER V: METHODOLOGY

*I must be true to myself. Strong enough to be true to myself. Brave enough to be strong enough to be true to myself. Wise enough, to be brave enough, to be strong enough, to be true enough to shape myself from what I actually am.*

Sylvia Ashton-Warner, Author and teacher (*Quotable New Zealand women*, 1994)

### Overview

This chapter describes the methodological steps for grounded theory that were undertaken for this research. In the first section the study design, aim and objectives are outlined together with an explanation of sample size, selection and the justification for the sample selection. The second section describes the qualitative interview method in terms of the selection of questions, the interview process and the interview structure. The third section identifies research procedures and links them to the initial consultation processes that are required for ethical approval. The fourth section discusses each stage of the theoretical development within the data analysis, related to data collection methods, the analytic process and coding procedures. The methodology is summarised at the end of this chapter.

### Introduction

Grounded theory methodology provides the researcher with systematic procedures for shaping the data while conducting a simultaneous process of inductive and deductive analysis. The phases of sampling, data collection and analysis are built up in conjunction with each other, stage by stage. This method uses the data to develop a theory instead of using the data to test a hypothesis. The emerging theory accounts for patterns of behaviour relevant to the phenomenon being studied.

The qualitative data was obtained from 30 participants. A theoretical model relating to European participants was developed after the first coding process. Maori in-patients were interviewed at the three hospital sites. Interviews were then conducted, in rotation, through the three Maori Health Trusts. The data records consisted of 38 hours of interviews recorded on audiotape, 300 pages of transcriptions, field notes,

and interview journals over a two-year period. Copies of transcriptions were sent to participants involving 20 hours of follow-up interactions with participants regarding the transcript reviews. The interview tapes were reviewed and issues discussed with methodology supervisors, which is the process of studying your data (Charmaz, 1990). Data gathering procedures are included with a description of interview pilot testing and the interview process. The importance of designing and carrying out a high quality interview process was an integral part of the design. Procedures for data analysis are described using the constant comparative method. Figures showing the analytic memo and independent category list are included with the data analysis.

### **Study design and aim**

A single cross sectional study was conducted with two samples (18 European and 12 Maori participants) at one point in time. The purpose of this qualitative study was to use the grounded theory approach to explore the reasons why women hesitate to seek emergency care for heart attack symptoms and whether this differs from men's approaches. In addition, a further purpose was to compare European with Maori experience of heart disease symptoms from the same perspectives hence participants were sought from both cultural groupings. To do this the researcher selected European and Maori participants. This study builds on the first Middlemore pilot conducted in 1997 (Campbell, 1998), which indicated that there was a need for further research on inaccurate perceptions of heart attack symptoms. In particular, this was seen to relate to women and Maori people both of whom tend to have more prolonged delays in reaching hospital with heart attack symptoms than European men.

### **Study objectives**

The following objectives were formulated:

1. To explore European and Maori women's recognition and understanding of premonitory and actual heart attack symptoms. This exploration will describe women's experiences of heart attack symptoms, what they believe is the cause of their symptoms, how they describe their symptoms to others and the length of time in seeking medical assistance.
2. To determine in particular, why women may not take the appropriate action

at the time of the acute event.

3. To determine differences, if any, in the above matters between European and Maori women and also between women and men from both ethnic groups.
4. As a consequence of the study findings, to be in a position to make recommendations to the Ministry of Health and The National Heart Foundation, if appropriate.

### **Ethical requirements**

Prior to beginning the research, ethical approval was gained from the Auckland Ethics Committee and the clinical boards at each hospital. All study information and consent forms were translated into Te Reo Maori (Maori language) for the Maori participants. The structure of the Maori invitations had to be changed around to suit Maori protocol. The ethical application stated that the first contacts with potential participants were to be made through General Practitioners, Practice Nurses, Cardiologists and Coronary Care Nurses. This condition was designed to reduce the likelihood of coercion to participate in the study by the researcher. It also met the requirements of the Privacy Act wherein people who were patients of a hospital or a General Practitioner would not have information disclosed about them to the researcher prior to their decision to participate. An ethics approval was granted in July 2000. A plan for counselling distressed participants was included in the ethics application. A further review by the Auckland Ethics Committee was conducted in July 2001 and approval was granted for the following year (2002).

### **Sample**

#### **Sample size**

In all, 30 people took part in this study. Among the 30 interviewees there were nine European women, five Maori women, nine European men and seven Maori men. Table 5.1 shows the final sample of the study participants. Participants were selected from primary health care clinics and hospital coronary care units that agreed to be involved during the initial consultation process. The specific number of participants from each setting with regard to gender and ethnic groups depended on the researcher's decision about the point where data saturation was reached. Five sampling criteria for inclusion, exclusion and eligibility criteria were established.

Each criterion is explained below, together with the underlying assumptions and rationale for this particular sample selection.

**Table 5.1: Sample of participants**

<b>Gender</b>	<b>European</b>	<b>Maori</b>	<b>Total</b>
<b>Women</b>	9	5	16
<b>Men</b>	9	7	14
<b>Total</b>	<b>18</b>	<b>12</b>	<b>30</b>

The sample number was made up of four groups (30 participants) which is illustrated in the profile of participants and data collection flow charts (See Table 5.1 and Appendix K). There were differences between the four groups. The majority of European participants were older and retired while the Maori participants tended to be younger, employed in physically demanding jobs or unable to work because of chronic illness. Five Maori participants aged over 63 years had reached retirement, which is important because Maori tend to die of cardiovascular disease at younger ages than Europeans (Bell et al., 1996). The group differences provided the opportunity to compare and contrast a variety of symptom experiences and coping activities surrounding care seeking for heart disease. The sample was dispersed throughout a wide area (Central, West and South Auckland) to provide important contextual information useful in the axial coding phase (Creswell, 1998). The final sample consisted of 30 participants (12 Maori and 18 European) representing four comparison groups: European and Maori, women and men (See appendix K).

### **Sampling methodology**

The researcher used a theory based sampling process (Creswell, 1998). Theoretical sampling is a form of purposive sampling; in this case with the aim that these experiences would contribute to the evolving generation of a theory about care seeking for heart disease symptoms. The sample consisted of four groups. The first group (European women) was the primary group for developing the theory. The other three (European men, Maori women and Maori men) were selected to make comparisons with the European women's groups. The data from the other three groups also contributed to theory development (Creswell, 1998). The overarching

principle that guided sample selection was the researcher's judgement as to how each group met the study objectives. There were various criteria that could have been used but these were not included in the sampling criteria (e.g. medication, occupation, socio-economic status, etc.).

## **Selection criteria and their justification**

### ***1. Gender***

Participants were selected so that there were similar numbers of women and men. In selecting participants, an effort was made to get similar representation of both sexes in both ethnic groups. Although the primary focus of this study is on women, it was of central interest to determine how women differ from men in the area studied. Therefore, it was important to interview equal numbers of women and men.

It was assumed by the researcher that women's experiences of heart attack symptoms are gendered and therefore the meaning of symptoms may be different for women than for men. The inclusion of similar numbers of women and men was intended to compare potential differences in symptoms experienced and care seeking for AMI symptoms.

### ***2. Age***

All participants were aged between 45 and 85 years. This age range was chosen to include the experiences of older women and men who have prolonged delays in care seeking for an AMI. It was assumed that heart attacks in women would be more likely to occur after 65 years of age. Conversely, Maori people are more likely to die from a heart attack at an earlier age (45 to 64 years). It was assumed that Maori participants needed to be recruited from 45 years of age to capture their experiences of heart disease symptoms.

### ***3. Ethnicity***

Participants were of Maori or European descent. The participants were selected so that there was similar representation of both ethnic groups. In the present research it was assumed that there might be differences in symptom reporting and delays in care seeking between Maori and European participants.

Ethnic affiliation was determined by the question: “To what ethnic group do you belong?” (New Zealand Department of Statistics, 1996). Only those who self-identified as European or Maori were included (see Table 5.1: Sample of participants).

#### ***4. Medical conditions***

Participants had to have been diagnosed as having angina, a high risk of AMI, or a previous history of a heart attack or a current admission to Auckland, Green Lane or Middlemore hospitals with a first AMI. It was assumed that some participants in the community setting might visit their General Practitioner to relieve angina or potential heart attack symptoms rather than seek emergency care.

#### ***5. Locations***

Community: European participants were drawn from six Primary Health Care Clinics: Meadowbank Family Doctors and Four Kauri Family Medical Centre (Central Auckland), Kinross Medical Centre and Avondale Family Doctors (West Auckland), Trust Health Care and Your Health Centre (South Auckland). Maori participants were drawn from three Maori Health Trusts: Ngati Whatua O Orakei Health Centre (Central Auckland), Waipareira Health Trust (West Auckland), Raukura Hauora O Tainui Ki Tamaki (South Auckland). Hospital: European participants were selected from three sites: Auckland, Middlemore and Green Lane hospitals. Maori participants were selected from Green Lane and Middlemore hospitals.

It was assumed that it was important to record a participant’s prior symptom experiences and care seeking behaviour before hospital admission for an AMI. Most studies investigating delays in care seeking had been conducted on easy to reach populations in hospitals. Therefore, participants were interviewed in community settings (General Practitioner clinics and Maori Health Trusts) and compared with interviews about participant’s experiences after an emergency admission to hospital. Middlemore hospital was chosen as a recruitment site for Maori as there was a greater likelihood of Maori admissions to the coronary care unit due to larger numbers of Maori residing in South Auckland.

## ***6. Cognitive status***

Participants needed to be alert and oriented and able to speak English or Maori adequately. Participants needed to be able to remember their symptoms or events during the onset of the AMI until their arrival at hospital, and be able to reflect on their own behaviour.

## ***7. Preliminary consultation process***

The researcher believed that extensive consultation in the design process was fundamental to the success of the project. The study was part of a wider collaborative research initiative on Women and Heart Health in association with Dr Fiona Stewart (Cardiologist) and others at Green Lane Hospital. Meetings were held with key health professionals in the selected General Practitioner clinics, and the Cardiologists and nursing staff at three Auckland hospitals to obtain feedback for final research design. The Maori advisor provided advice about the study, the interview schedule and proposed data analysis and consultation with the Maori Health Trusts. The proposal had widespread support in the medical, Maori, academic and community spheres.

### **Consultation about recruitment of participants**

The researcher held a series of meetings to discuss the criteria for recruitment into the study, and to establish recruitment procedures. Additional time was required to discuss the need for uniformity in various primary care settings where clinical routines and participant profiles differed widely. When the proposed date for recruitment of participants from each site was known, all key medical staff received written notification and a copy of the ethical approval. For the purposes of recruitment, medical staff were provided with the two standard information sheets for the study (see Appendix C and D). The hospital information sheets were given directly to participants by nursing staff. If hospital participants agreed to participate in the study, the nurses would contact the researcher who would meet participants in the ward. Information sheets were posted to selected participants by Practice Nurses from General Practitioner clinics. The Practice Nurse made a follow up phone call to each participant. The participants gave verbal consent for the researcher to contact them by telephone. This was the first direct contact made by the researcher.

### **Interviews with Maori key informants**

Prior to interviewing people with heart disease, the researcher decided to obtain Maori views about the heart, the traditional ways of treating the heart and its symbolic meaning for Maori. It is important to acknowledge that these interviews were not conducted lightly. The researcher was only given permission to interview three respected elders as authorities after each person had thoroughly tested her motives for seeking such privileged information. The researcher had a strong sense of family, being of Scots lineage and born into large clans related to each of her parents. The researcher related how her ancestors had travelled to New Zealand. The researcher's work history and involvement with Maori required explanation. More specifically, the researcher had to explain how the research was set up, what consultation process had taken place and how the research would be accomplished using Maori researchers and Maori advisors to analyse the data. Finally the researcher had to state how the findings would be disseminated and how Maori would have ownership of their data.

As a skilled and experienced interviewer who enjoyed the 'mainstream' interview process the researcher was taken into a different world. The Maori doctor chose to adhere to European 'mainstream' protocol in his workplace so the interview was short and straight to the point. Two of the sessions started and ended with a karakia (prayer). The Kaumatua (male elder) chose to be interviewed at home with tea and scones set out as a welcoming meal. The Kuia (female elder) chose to be interviewed outside in a park under a tree where she felt close to the whenua (earth). The transcripts were analysed using the constant comparative method to identify common themes (Thomas, 2003). It was vital for the researcher to leave as much of these interviews in the language and form handed down to her by the Maori elders.

### **Qualitative interviews**

Thirty qualitative face-to-face interviews were conducted between October 2000 and December 2001. The interviews were conducted using a semi-structured interview schedule as described below.

#### ***Selection of questions***

An interview schedule containing open-ended questions was developed. The interview schedule followed the sequence of events that leads to seeking care for

heart-related symptoms. The question wording of questions was altered to encompass either the hospital or community setting, for instance the word heart attack used in hospital interview schedule was changed to angina, or heart disease for the community interview schedule. The schedule may be found in Appendix A and B.

The interview schedule was based on:

- Leventhal's (1997) theoretical explanatory framework of illness response and Horne's (2000) interview schedule.
- The interview schedules contained additional questions drawn from the ARCOS studies, (Doggen et al., 1993) and the Brighton study (R. Norris, 1999).
- Meischke's (1995) research, and the researcher's previous research (Campbell, 1998).
- They included specific questions about the 'first thing' (H. Meischke, Eisenberg et al., 1995) people do in response to their symptoms, what information they received from their doctor, and their perceptions about their risk of having angina or a heart attack.

The schedule covered symptom descriptions, beliefs about the causes of the symptoms, and coping actions that influenced care seeking. Examples of several of the questions asked in each of those six categories now follow:

1. The symptom descriptions (causal conditions): "Could you please describe what happened from the first time you first noticed the symptoms?" "Could you describe your symptoms for me?" Causal conditions that influenced the central phenomenon were gender and ethnic differences in feelings about the seriousness of the symptoms and perceptions of control.
2. The symptom attributions (causal conditions and perceived consequences): "What did you think was going on when the symptoms first started?" "Could you tell me why you believed it was (labelled condition)?" The majority of participants did not believe that they were experiencing life threatening symptoms so they did not contact emergency services.

3. The intervening conditions and the social context: “Who else was with you when you were experiencing these symptoms?” “Did anything stop you from going to the clinic earlier?” In the broader context, the family dynamics and the participant’s gender, ethnicity or age, were the variables that influenced coping strategies.
4. The coping actions: “What was the ‘first thing’ that you did when you noticed the symptoms?” “Who made the decision to contact the clinic?” “How did you get to clinic?” In the narrower context if participants experienced symptoms whilst alone they treated themselves with rest or medications. When the symptoms broke through these self-treatments they consulted friends or family. In the broader context, consultation with others established intervening conditions such as contacting the ambulance. These conditions subsequently influenced actions.
5. The perceptions about the consequences of the illness: “Could you tell me how severe do you think your angina (or heart disease) is?” “What chance do you think you have of having a heart attack?” “How easy is it for you now to accept that you have angina or heart disease?” These questions were designed to elicit the meaning of the participants’ experiences of heart disease and the personal impact of the diagnosis of heart disease.
6. The participants’ views as part of the research: A final question allowed for the participants to contribute to the interview in their own way: “Is there anything else you would like to tell me about your angina or heart attack?” Differences between women, men and Maori about the consequences of their heart disease impacted on their perceived ability to heal, recover and control their symptoms.
7. Measurement of hospital delay times: The delay time between first noticing the symptoms to entering a clinical service was measured in both interview schedules. Four delay times were covered in the hospital interview schedule which are identified as delay times a, b, c, and d. Delay time (a) can be measured from the period between symptom onset and the time that help was

summoned; Delay time (b) was the difference between the time of the call for help and the time that the worst symptoms occurred; Delay time (c) was the period between the participants' realisation that they may be having a heart attack and the call for help; and Delay time (d) was the interval between the first symptom onset and the time of the hospital admission. For this study, only the delay time between symptom onset and hospital arrival (delay time d) has been measured. Delay intervals for the hospital study were taken from participants' self reports and checked against hospital clinical records and ambulance reports.

8. Measurement of community delay times: One delay interval was measured in the community interview schedule, which was the time of the first symptom onset until the time of the clinic appointment. These delay times were measured according to the participants' self reports and were considered as an approximate indication of time only (See appendix A and B).

### ***Pilot testing***

The initial participants were chosen for a pilot interview using the theoretical sampling technique (Charmaz, 1990; Creswell, 1998). The schedules were "Response to your angina, or heart disease symptoms" used in the General Practitioner clinics and the "Response to your heart attack symptoms" used for hospital patients (See appendices A and B). The aim of the pilot interviews was to verify the appropriateness of the interview questions, the interview length (approximately 45 minutes) and to review the quality of the field data. The interview schedule questions were modified for the remaining interviews (See Appendix L data collection charts).

### **Data collection process**

#### ***Data collection timeframe***

The researcher collected the interview data by making multiple visits to the field. Ethical approval for the research was gained in July 2000. The recruitment of participants, fieldwork and data collection commenced in August 2000. The 18 European participants were recruited between August 2000 and November 2001. The 3 Maori key informants were interviewed between August 2000 and September 2000. The 12 Maori participants were recruited between June 2001 and December 2001.

The preliminary findings were accepted for presentation at the International Congress of Behavioural Medicine in December 2001. Data analysis was conducted from January 2002 to November 2002.

### ***Interview locations***

Interviews with European and Maori participants were conducted at selected General Practitioner clinics and Maori Health Trusts located close to the homes of the participants. The decision to use clinic rooms for the interview was based on a number of issues. Primarily, the local medical clinic was centrally located in the recruitment area, and was a place that participants felt familiar with because it was where they received regular check ups. It was also convenient for the researcher to access the medical records before and after the interview to compile field notes and to attach the consent forms to the notes. For the purposes of confidentiality these records could not be removed from the clinic premises. The clinic room provided some elements of control for the researcher and the Maori interviewer. It was easier to monitor the quality of recording because the rooms were usually situated some distance from the reception desk, were carpeted and thereby insulated from the noise of traffic. Using the doctor's office provided some psychological safety for the participants. An additional benefit was that there was control over distractions such as interruptions from clinic staff or family members.

The Maori Health Trusts were a place where Maori whanau (extended family) were made welcome. Field observations showed several differences to European clinics. Loud and cheerful greetings interspersed with jokes were exchanged between staff the family and their patients. These greetings were often made in a mixture of Maori and English. Time was also used in a different way. Maori patients were given extra time to settle in at the clinic before their examination or interview. People entering their clinic would discuss everyday events intermingled with stories relating to their whakapapa (ancestors). Whanau (extended family) consisting of young and old members would stay in the waiting room while participants were interviewed.

### ***Hospital interviews***

The decision to use coronary care units and medical wards was driven by the traditional admitting system for cardiac emergencies (See data collection chart

Appendix L). There were uncertainties for both the researcher and the participants in the hospital environment. Hospital patients had experienced an acute event, so they were only just beginning to come to terms with their health crisis and were in a vulnerable state. The researcher checked with participants about their feelings and emotional state before proceeding. The researcher accessed the medical records before the interview, which provided an opportunity to liaise with ward staff. The interaction time with ward staff was used to determine if the prospective interviewee was well enough to be approached for an interview. In general, medical wards have a busy atmosphere. To provide some privacy curtains were drawn around the bed. Some interviews took place in the coronary care units. They were a little quieter than medical wards but the constant beeping of equipment monitors underlined the fact that it was an emergency facility. The interviews were conducted with some background noise and the threat of constant interruption by ward staff whose lifesaving duties took priority over the research. It was difficult to monitor the quality of recording.

### ***European data collection***

The European interviews (women and men) were undertaken first and spread over the Auckland region. The interviews were conducted with one woman and one man from each site.

Phase one: The data collection process began with interviews 1-6, six European participants (3 women and 3 men) in South Auckland. This involved one hospital (Middlemore) and two clinics (Clinic 1 and Clinic 2).<sup>2</sup>

Phase two: In central Auckland, interviews 7-14 were conducted four (2 women and 2 men) at clinics (Clinics 3 and 4) and four at hospitals (2 women and 2 men at Green Lane and Auckland hospitals respectively).

Phase three: In West Auckland, interviews 15-18 were conducted at Clinic 5 and 6. Note that the first four of these six interviews were used as pilots to test and modify the interview schedule (see pilot testing on page x for more details). (Note that a

---

<sup>2</sup> See the Selection Criteria and their justification for the names of clinics participating in the study.

schematic representation of this and the following phases is provided in Appendix L) The above phases provided the first two groups of the overall sample of 18 participants, Group 1 European women and Group 2 European men. The characteristics of these two groups are shown in Appendix K. To summarise, Group 1 consisted of 9 women aged between 57 and 79 years with a mean age of: 71.3 years. Group 2 consisted of 9 men aged between 46 and 80 years, with a mean age of 56.4 years.

### ***Maori data collection***

After the initial theory was developed, the researcher began to select and analyse the second two groups (Maori women and men).

Phase four: The first interviews with eight Maori participants (interviews 1 to 6, 9,10) in South Auckland were conducted at Maori Health Trust 1<sup>3</sup> and Middlemore Hospital. The last two participants were selected from Middlemore Hospital. The Maori interviewer decided in consultation with the researcher that Maori participants could choose to be interviewed at home if they felt more comfortable. Two women participants at Middlemore Hospital chose this option although one woman later declined an interview at home.

Phase five: In the Central locality six interviews (interviews 7, 8, 11 to 14) were conducted at Maori Health Trust 2 and Green Lane Hospital. One man decided to be interviewed at home.

Phase six: In West Auckland four participants (interviews 15 to 18) were interviewed at Trust 3. Note that the first four interviews were used as pilots (see pilot testing on page x for more details). (Note that a schematic representation of this and the following phases is provided in Appendix L) Phases 4, 5 and 6 supplied the second two groups of the total sample (17). Group 3, Maori women and Group 4, Maori men. The characteristics of Groups 3 and 4 are shown in Appendix K. Group 3 consisted of 9 Maori women aged between 45 and 72 years with a mean age of 59.1 years.

---

<sup>3</sup> See the Selection Criteria and their Justification for the names of Maori Health Trusts in each locality.

Group 4 comprised of 9 Maori men with ages ranging from 46 years to 81 years with a mean age of 60.4 years.

### *Clarifying the interview process for participants*

The researcher had prior telephone contact with participants prior to the interview and was able to explain what was going to happen at the appointment time. Although the study invitation and the telephone contact set the scene for the clinic visits it was not possible to remove some elements of uncertainty for the participants. Before individual interviews were started the researcher checked for uncertainty about the purpose of the meeting by going over the study invitation with participants. Some uncertainties became apparent during this introductory phase. For instance, a few participants had brought their medication with them, one participant believed that a medical examination would be conducted during the interview and other participants expected to have some health education about heart disease. These uncertainties may have been less of a concern to participants if they had been interviewed in their homes where they were in familiar surroundings. However, feedback from the participants after the clinic interviews was positive. The subsequent audio recordings were all of adequate quality for accurate transcription except for five Maori interviews.

Prior to opening the interview the researcher engaged the participant in friendly polite conversation by demonstrating an interest in them, to build rapport. Oakley (1981) describes this rapport building technique as being friendly but cautions about being too intrusive or over friendly. Egan (1990) terms this stage as engaging the person but conducting the interview according to professional requirements. The researcher explained the study purpose, the consent forms, the audio taping procedure and the interview process. Written consent forms were signed and witnessed. The ground rules of the interview were discussed placing emphasis on participants' control of the interview, such as stopping the interview.

### *Identifying interview dynamics*

The interviews were audiotaped and no written notes were taken. Instead the interviewers became actively involved in the interview, listened closely, and were attentive, in order to draw out or facilitate participants' recall of events. A conscious note was taken if a topic or concept emerged from the discussion. After the interview

was finished, handwritten notes were made about any observations. For instance, noting how comfortable the participant was with relating personal feelings about their heart problems. These notes were expanded after reviewing the audiotape. Several cues alerted the researcher to important clues in the dialogue: tone of voice, emphasising feelings, repeating parts of their story or remaining silent.

The researcher used reflexivity or self-awareness when conducting the interview encounters. An example of reflexivity (Charmaz, 1990) was to acknowledge the importance of participants' stories. Charmaz (1990) notes that being too directive in an interview can cut off leads to the yield of rich data. During the initial period of the interview there was a significant level of participant anxiety about the questions. Some of the participants checked with the interviewer as to whether they were giving the correct answers to the questions. The interview was temporarily suspended while the interviewer discussed their concerns and explained that there was no right answer for the questions. The anxiety of participants was treated with gentleness, patience and respect, which sometimes added to the interview length. Some of the men had cried after their interview was over because they had not had the opportunity to confide in anyone about their painful symptoms and fears about dying. These events were discussed at supervision meetings. The researcher reinterpreted her thinking and the special nature of the interview narrative was respected. These interpretations were subsequently supported by observations that women and men shared their private experiences and feelings with the researcher, in the hope that it may help other people in the future. Most participants commented that they found the interview gave them a chance to reflect on the impact of their diagnosis and they felt relieved.

The Maori interviewer would settle the participant by conducting the interview according to Maori protocol. The Maori interviewer introduced herself and identified her tribal affiliations. She described the process as doing a mihi (greeting) and waiting for the participant to reply. From this mihi the Maori interviewer would gauge the participant's response as to whether they would prefer to speak Maori or not. The reciting of a karakia (prayer) gave the interview an appropriate Maori opening and set the stage for allaying Maori fears about discussing symptoms. Similarly, the interchange of Maori and English dialogue was an important difference in the interviewing process. It allowed Maori to express themselves with words that

may not smoothly translate to European terms. The interview concluded with another karakia (M. Durie, 2001). The transcripts showed that some Maori participants had whispered when discussing symptoms and they had requested that the tape be stopped from time to time during the interviews.

Several methods were used to promote reflection and review of both the researcher's and the Maori interviewer's sessions: (a) An advisory team was established. This team consisted of two supervisors and one Maori advisor (a behavioural psychologist, a senior advisor in qualitative methods and a senior Maori health researcher). (b) Regular meetings were held with the qualitative methods supervisor to discuss the methods used and the issues that surfaced in data collection. (c) Both supervisors and the Maori advisor reviewed the written transcripts. (d) The researcher kept a field diary of events, field observations, thoughts and feelings, and how these might be influencing the researcher's interpretations. (e) A separate diary was kept to record interview debriefings with the Maori interviewer and comments by the Maori advisor. During debriefings with the researcher the Maori interviewer provided feedback about Maori ways of conducting the interview. The Maori interviewer began to gradually feel more comfortable with using Maori terminology and to change the interview questions so that they were more direct and appropriate for Maori. During the Maori interviews the researcher made written observations from the medical notes and about the clinic. After the interview session there was shared discussion and notes were written up.

### **Data saturation**

The interviews continued until the researcher considered that the data had reached saturation point where there were no new symptom descriptions, symptom attributions or coping actions. Incidents that were not typically related to the theory were re-examined. Two case examples were: 1) where an older woman had collapsed and been transported to hospital promptly and 2) where another older woman's daughter immediately called for an ambulance. Data saturation was reached because the researcher could not find any further data to add to the theory development (Charmaz, 1990; Creswell, 1998).

## **Data analysis**

### **Theoretical decisions**

This section describes the theory development of ‘Recognising women’s responses to heart disease symptoms: different groups respond in different ways’ from the raw transcripts data, the coding process through to the final meta-theory. The theoretical development was not a linear process. Data analysis was driven by the researcher’s standpoint (a European woman with Scottish lineage) and the systematic rules of grounded theory. The combination of the researcher’s inductive thinking and deductive analysis can be described as weaving a tartan (Buchan, 1975). The origin of tartan is not known but it has been intertwined with Scotland’s history from around the 12<sup>th</sup> century. Tartan is a woollen cloth with a highly stylised design that represents a powerful symbol on the world stage. Its patterns have deep meaning for those born into a clan. The pattern of data analysis emerged from the constant weaving and reweaving of symbolic pieces from participants’ worlds to become a stylised set of codes for survival (Buchan, 1975). The pattern wound its way through many a multiplicity of small decisions to become the final data map. The following record of theory development has been condensed to illustrate the analytical process.

### ***Data, analysis and writing***

The analytic process was based on immersion in the transcript data, repeatedly sorting and comparing the texts (constant comparative method) (Creswell, 1998). Thomas (2003, p. 2) has identified that qualitative data analysis has three main purposes:

1. To condense extensive and varied raw text data into a brief, summary format.
2. To establish clear links between the research objectives and the summary findings derived from the raw data and to ensure these links are both transparent (able to be demonstrated to others) and defensible (justifiable given the objectives of the research).
3. To develop a model or theory about the underlying structure of experiences or process which are evident in the text (raw data).

The researcher’s school of thought, values and emerging ideas were reflected in the coding and categorising of data. The researcher’s social constructionist perspective linked to feminist analysis (Charmaz, 1990; Ussher, 1999) fostered the creation of

categories around the beliefs and actions of participants (See Chapter Four: Grounded Theory Rationale).

The data analysis process is discussed in three stages. The analysis commences with the initial sampling stage, which is followed by the axial coding stage and the third stage covers further development of the theoretical model.

#### Stage one: Initial sampling

Sampling and analysis are interrelated processes. Open sampling commenced with the selection of participants most relevant to the research question (See appendix L, data collection charts). Each participant's interview was audiotaped and transcribed verbatim and saved on a data file. Then the next participant was selected and interviewed. All raw data files were saved in a common format (data cleaning) and imported into the NUD\*IST software (Thomas, 2003). The transcripts were read, reread and scrutinised several times to identify common themes (constant comparative method) (Thomas, 2003). The researcher looked for a concept that was a pattern within a set of descriptive incidents. The data was conceptualised by comparing incident with incident then incident with concept that allowed more categories to emerge. Categories are concepts that are used to obtain a higher level of abstraction. In each category the researcher identified a number of properties or sub-categories and examined the data to show numerous scenarios that either supported or contested the category (Creswell, 1998; Glaser, 1992; Glaser & Strauss, 1967).

The pilot interview data was coded first. The first stage of analysis was open coding where the researcher formed initial categories by segmenting information about the phenomenon being studied (Creswell, 1998). In the initial stages the researcher was faced with an overwhelming amount of data so open coding was a way of ordering raw data with no preconceived ideas. This process helped the researcher organise and contain the large amounts of text and focus on what the data was saying.

The two questions about symptoms were open ended: Could you please describe what happened from the first time you noticed the symptoms? Could you describe your symptoms for me? These questions allowed participants to answer in their own terms without imposing assumptions about what happened or providing medical symptom

labels. A theoretical decision was made to code the symptom descriptions and coping strategies. It looked too routine and too simple. The researcher's first thoughts were that she was repeating what was done before and not getting fresh insights. Paying close attention to 'real life' symptom descriptions and how people coped with them revealed the initial discoveries. These categories were capturing social actions and interactions close to the phenomenon. What was of tremendous interest to the researcher - was that these descriptions were 'pure' and had not been tampered with by investigators. For example, when presenting symptoms are recorded in medical notes medical terminology is used. In the case of a European woman aged 58 years, the differences in symptom descriptions show communication difficulties about the pain where the medics incorrectly recorded a diagnostic term like "*Chest pain radiating to left and right shoulders*" in contrast to the participant "*the tops of my arms started to ache, not my shoulders but the tops of my arms*". The discrepancies in symptom descriptions were revealed by studying the two major sources of information (participant dialogue and medical records from the field notes) relating to the 'delays in seeking medical help' phenomenon, rather than just examining how people got to hospital which is a more general topic (Glaser, 1992). The open coding process helped the researcher to break open the data and construct analytical questions about it (Charmaz, 1990). Three strategies were used in the grounded research process:

1. Researchers pay close attention to the data, which is viewed as a series of discoveries.
2. The theoretical analyses build on their interpretations of the process within the data.
3. They compare their analyses with the literature (Charmaz, 1990, p. 1165).

The researcher used Charmaz's (1990) question model as a way of breaking into data meanings. This strategy assisted with data interpretation, which was the inductive component in the data analysis (Thomas, 2003). The questions were:

1. How do the participants construct or define their symptoms? Who benefits from these descriptions?
2. How do participants define their control over symptoms? What way do participants' constructions relate to their conceptions of control that reflect larger ideologies?

3. How do their constructions change over time and number of symptom events?
4. What are the differences in language?
5. What are the differences in coping strategies?
6. What consequences emerge from their constructions of control?

#### *Building up the qualitative data set*

When each interview was completed they were coded using the QSR NUD\*IST<sup>4</sup> computer-based software package. This software had five functions: storing and organising each transcript file imported from a word processing programme, searching for themes, crossing themes, diagramming and creating a template (Creswell, 1998). The software package was used as an analytic tool to assist in the coding process. Lines of text that formed one unit were the mechanisms that divided interview data. The software contained two analytic components: a document system that allowed the researcher to store the field data and an index system that assisted the researcher to create categories. Collation of information was ranked using grounded theory (Charmaz, 1990; Creswell, 1998) by taking the individual transcripts for the particular question and grouping the data according to the interview sequence (data reduction) (Creswell, 1998). A pattern of categories began to emerge from the text from the initial analysis conducted in the pilot stage.

#### *Initial coding phase*

The researcher used the women's language in the symptom descriptions and coping strategies to guide the open coding process. In searching for themes with the database the researcher was able to find all of the information relating to the first, single theme. The first theme was the symptom descriptions. Texts from transcripts were merged into the symptom descriptions category. The categories were labelled with a word or phrase and identified with short descriptors called in vivo codes, which contained key characteristics and any limitations (Creswell, 1998; Thomas, 2003). In vivo coding involves creating categories from units of meaning units or actual phrases in the text (Thomas, 2003). Coded text associated with the category illustrated the meanings for participants, their associations and perspectives (Thomas, 2003), relevant to that

---

<sup>4</sup> Qualitative Solutions and Research Pty Ltd., is the licensed distributor for the software Non-numerical Unstructured Data\* Indexing Searching and Theorising (NUD\*IST) [www.qsrinternational.com](http://www.qsrinternational.com)

particular theme. Some of the text was coded into similar categories, for instance the categories: symptom descriptions, pain experiences and beliefs about symptoms contained overlapping text. Not all of the text was coded, for example, if participants talked about the number of blood tests they had over a specific time period this data was superfluous and not relevant to the study objectives. The researcher recorded the analytical process in a journal. (For more details, see the analytic memo box, Figure 5.1 on page 110). An important line of thought was contained in the following questions. What was to be proved? Where were the meanings? Participants were recounting their health crises in plain, everyday language. On the face of it, things appeared to be quite mundane.

How could an emergency crisis be related to a series of women's statements about symptoms that were run-of-the-mill or vague? These two examples demonstrate the language used to describe heart symptoms, which provided the first clue.

*I didn't feel good at all. Just blah. Well I thought that I had been sleeping the wrong way.* (European woman, 76 years - Retired)

*I wasn't feeling very well at all. I thought I was going down with the flu. I felt absolutely run down.* (European woman, 71 years – Retired)

The first discovery:

Language was the first key to unlocking the puzzle. A closer look at the descriptions was required. Further interviews were conducted to elicit symptom descriptions that were similar to the above example and other interviews were screened for exceptions for instance another woman described “ a heavy feeling in her chest” which was closer to the classic AMI symptom presentation. Another similar example was from a man.

*Occasionally I might get that you know heart burn it might get a bit tight and it might just come and go in a matter of minutes. Probably more like indigestion. No real symptoms.* (European man, Manager – 48 years)

The researcher's analysis returned to a review of the interviews of each European woman. Their data was viewed as a valuable source of knowledge in its own right (feminist analysis) (Ussher, 1999).

As previously mentioned, the theoretical sample continued to be built up with additional interviews. During the interview process, close attention was paid to the actual words used in women's symptom descriptions and pain experiences, then compared to men's. The researcher's prior understanding of heart disease symptoms (common and uncommon) (H. Meischke et al., 1998) influenced the close focus on the way symptoms were described. The mundane language often overlooked by previous researchers' assumptions was an important influence on care seeking and responses from the medical profession. Doctors were not hearing women when they were uncertain or confused about their symptoms. Symptom descriptions appeared to be the single category relating to the central phenomenon (Charmaz, 1990; Creswell, 1998).

#### *Building up independent categories*

The interviews continued and the researcher used the observations from the analytical memo to explore the raw data. The researcher used relational or variational sampling to gather more data to disconfirm or elaborate the emerging theory. A list of questions was used to examine the data more closely. Two examples are: 1) Are there differences between individuals with their pain experiences or symptoms? 2) What is their personal history or experience of illness? (See Figure 5.1: Analytical memo box for more details).

Emerging themes were developed by reviewing the transcripts and reflecting on possible meanings and how new meanings fitted with the existing categories. If a significant new theme emerged the category frame was changed. The 26 independent categories were built up and the text continually studied. (Figure 5.2 shows the 26 independent categories on page 115). This created a diagram of categories, which helped the researcher to visualise the emerging themes. Each independent category was a labelled category containing several properties or subcategories that showed all of the dimensions across a continuum (Creswell, 1998). The independent category contained every labelled text segment either confirmed, denied, explained or was at

odds with the way socially constructed perceptions of symptom descriptions were coming out of the data.

**Figure 5.1: Analytical memo box**

### **20.5.01 Analytical memo**

#### **Definition of symptom descriptions**

The Oxford Dictionary describes a symptom as: “perceptible change in the body or its function indicating injury or disease. A sign or token of the existence of something.” (Fowler & Fowler, 1962)

There are different descriptive terms for major and minor symptoms. For example, minor symptoms can be termed as niggles or not feeling well. Major symptoms are described as unbearable. *Look for more terms here (e.g. fear or new words for symptoms)*

1. Pain or symptoms can precipitate worries or fears of death and fear of troubling people.
2. GPs or Cardiologists do not hear women. This is partly because women tend to be vague in describing their symptoms and partly due to the medical practitioner’s actual response to vague or uncommon symptoms. Medical practitioners can dismiss uncommon symptoms.
3. People delay in seeking care (men and women) because of their beliefs about their symptoms. They put it down to indigestion or some other cause.
4. Women use more self-treatment strategies - they rest, limit their activities, or self medicate.
5. Men tend to dismiss their minor symptoms. They do take action with major symptoms. For example, an episode of bad pain will result in seeking prompt medical attention. Did not relate pain in the jaw throat or back with angina or a heart attack. These symptoms resulted in confusion and delay in seeking care.
6. Women had no previous experience with which to compare heart symptoms. Their symptom experiences were with pregnancy or gynaecological conditions. This influences their care seeking and can result in lengthy delays.
7. People discuss their symptoms with someone else. *Check this out*

**Figure 5.2: List of independent categories**

<b>Symptoms</b> Pain experience Symptom descriptions Perceptions Maori symptoms Expectations
<b>Everyday Coping</b> Physical activity Fatigue Self treatment Scars Maori medicine Maori clinics Whanau
<b>Lack of Knowledge</b> Knowledge Lack of Knowledge Expectations
<b>Communication</b> Guilt Fears Optimism General Practitioners Collapse Embarrassment Anger
<b>Outcomes</b> Hospital experiences Transport Expectations Demographic information

Women and men talked about symptoms differently, they perceived them differently and both groups behaved according to their personal experiences of pain. Women reverted to patterns of enduring the symptoms as in menstruation or childbirth by referring to them as though they were a mild condition and resting between bouts of pain. Men had to be encouraged to name the symptoms and then down played them. The text was scrutinised for evidence of participants' psychological or social

concerns, i.e. the way they felt about their symptoms and how that related to their wider family or social network. Women talked about family obligations, support or discussed their situation with daughters, while men were reluctant to talk about symptoms until family members observed their pain and took action. A directed selection of participants and data from various sites helped to verify the categories such as comparison of symptom descriptions, emotions, knowledge levels and coping actions across the field sites.

#### *Difficulties with assigning meaning in the inductive coding process*

The researcher compared men's everyday language with women's everyday language and a picture of differences in symptom descriptions emerged. Men were reluctant to discuss symptoms and tended to downplay their symptoms, which contrasted with women who talked more freely about their symptoms. One part of theory development, the everyday coping category, was directly related to strategies and consequences within the axial coding system. When asking people what they did about their symptoms, there were different meaning units within their responses. People's expectations about their symptoms influenced what action they took. The researcher found it hard to assign this text into a single category. It evolved that expectations shaped actions in three stages of the model. *"I was finding it difficult going up the stairs and then I would get pain. But then, I thought, aw gee something's happened to my hiatus hernia you know"* This woman had described her expectations about symptoms which were shaped by her past symptom experiences or knowledge, and her beliefs. This section of text was assigned to categories: pain experience, perceptions, expectations, and lack of knowledge. Then a second set of expectations came to light when she was treating herself and arranging to see her doctor. *"I was taking Mylanta (indigestion remedy) of all things. Oh I didn't feel well so I called in to doctor and um the blood pressure was up everything was"*. She expected her indigestion remedy to relieve the symptoms and she expected reassurance from the doctor. This text was assigned to everyday coping and communication. The category expectations was present in the initial context when symptoms were first experienced, in the intervening conditions where people used their own health knowledge or sought reassurance and in the outcomes where people expected to experience the consequences of their symptoms.

### *Building up Maori codes and first discoveries in the Maori data*

In the second part of the data collection when Maori were interviewed, other categories were added (in consultation with the Maori researcher and advisor).<sup>5</sup> These additional categories were: Maori symptoms, Maori medicine, whanau, Maori clinics. During the Maori open coding process the same analytic memo (20.5.01) was used to order the data. This memo was discussed with Maori colleagues as to its suitability for analysing the Maori text. Maori transcripts were revealing another set of different categories relating to the phenomenon: Maori language was used in symptom descriptions; Maori showed a greater reluctance than Europeans to discuss symptoms and consultation with whanau was considered important.

### Stage two: Axial coding

#### *Building up the index of categories*

The categories were built up to form an analysis of the data that moved from independent codes with descriptive notes to higher levels of abstraction (Charmaz, 1990). The independent categories were grouped into five larger categories: symptoms, everyday coping, lack of knowledge, communication, and outcomes. (See Figure 5.2) The analysis moved from open coding to axial coding where interrelationships between categories are explored. Data was organised and coded into common themes (axial coding) then selected into categories and sub-categories, using the QSR NUD\*IST programme. (See section on the computer database.) Charmaz (1990) describes this phase as sharpening up the categories. Some essential elements are required to examine the data within a theoretical framework. These are the causal conditions that influence the central phenomenon, the strategies for addressing the phenomenon, the context and intervening conditions that shape the strategies and the consequences of undertaking the strategies (Creswell, 1998).

Data was coded into common themes (axial coding) then selected into categories and superordinate, parallel and sub-categories (Thomas, 2003). Comparing common themes, meanings and causal relationships made the links. This process facilitated the

---

<sup>5</sup> At all stages of the Maori data analysis consultation meetings were held with the Maori researcher and the Maori advisor. The consultation process made for a slower analytic process but it revealed significant meanings for Maori.

interpretative coding of data for the researchers by constantly reflecting on what was happening for the participants.

When the researcher reached the point where all of the data was coded, focused coding was used to cluster the initial codes under larger abstract concepts (Creswell, 1998). This process involved sorting the independent categories into a hierarchical index system on the database. The independent categories were clustered under more abstract headings. The following description highlights the six elements that are components of rigorous theory building through the construction of more abstract concepts. These elements are the conditions that influence the initial context when symptoms are experienced, and what intervening conditions affect the consequences, and outcomes, which are the resultant prolonged delays to seek medical assistance. The elements were:

1. Causal conditions: The conditions influencing the central phenomenon of delay to seek medical care for heart disease symptoms were located in the initial context. These causal conditions were coded into more abstract categories. The codes were grouped together as subcategories under each abstract category. The following category labels are: perceptions about the cause of the symptoms, symptom descriptions which refers to actual descriptions, vague and uncommon symptoms, beliefs which contain gender and ethnic differences in about symptoms, fears and expectations about symptoms.
2. Context: In the broader context the more abstract categories for intervening conditions were developed and linked to subcategory hierarchies of relevant independent categories. One set of categories for the intervening conditions was: personal experience, expectations (about symptoms) lack of knowledge, medicines (what prescribed or non prescribed medicines participants were using). The complex process of dealing with symptoms is reflected in the number of categories representing aspects of care seeking. Under each of these categories were related sub-categories.
3. Conditions: Categories for intervening conditions relating to care seeking were: communication, language, dismissive, health messages, confusion about symptoms, power, fears and symbolism about symptoms, different

experiences, different socialisation, different preferences for dealing with symptoms.

4. Consequences: Another set of categories was developed for coping actions related to the initial context and the intervening conditions. These categories were everyday coping actions, GP visits, double burden (relating to women's experiences), information, self-treatment and transport. Each of these categories for coping strategies contained relevant groups of subcategories from the independent categories. The consequences were related to the outcomes of coping strategies for symptoms. The following outcomes were: finding relief for the problematic symptoms or a complex array of attempts to deal with symptoms resulting in lengthy delays.

#### Stage three: Further development of the model

At this point the researcher's view of the findings was that the differences in responses to heart symptoms were confirmed by the grounded data. A process of selective coding began where the researcher integrated the categories in the axial coding model to represent the theory (Creswell, 1998). The theory contained a causal network where one category caused changes in another (Thomas, 2003). The abovementioned process was used to code and sort European and Maori data in conjunction with the Maori consultation process. The main finding showed the underlying message to be that people had preferences for survival and they behaved according to their social roles. Participants had perceived that their survival was a matter of life and death if the pain was intense enough. So coping strategies either reflected this or, if symptoms were mild or intermittent, they were not acted upon. They weighed up the consequences (positive or negative) of their coping strategies before embarking on a particular course of action. Charmaz (1990) refers to this process as an interaction between the researcher's knowledge or understanding and the research participants (M. Murray & Chamberlain, 1999). If the data was taken at face value, all it revealed was that the research consisted of more study participants who had prolonged care-seeking delays. It was by delving into the meaning of their actions that the patterns and codes for age-old survival are brought up into the light of researcher intuition and deduction. The findings in the results chapters will show that Maori were extremely reluctant to talk about their symptoms. Appendix M shows a diagram of this stage of theory development where the missing links are highlighted.

As the researcher refined the theory a hard spot emerged. How were the findings that Maori were using preferences for survival that centred around their beliefs of tapu and noa to be reported? European missionaries had defined these terms as sacred and profane (M. Durie, 1994). How were superstitious concepts connected to the self-regulatory model of illness to be explained? (H. Leventhal et al., 1999). It was necessary to take a break from the data and scrutinise the relevant literature for an explanation of Maori beliefs. Professor Durie's published material provided the answer.

His explanation was that Europeans had used the terms for tapu and noa in only one sense (sacred and profane). He went on to explain that tapu and noa were survival codes that meant safety and risk to Maori (M. Durie, 1994, 2001; M. H. Durie, 1985). The final pattern emerged. Participants were using cognitive rules with Maori using their own cognitive rules to cope with symptoms. After discussing the Meta theory with the principal supervisor, the researcher went back to review the literature taking some suggestions from the expertise of the principal supervisor. There were rules set for relationships (Argyle & Henderson, 1985) that fitted with the "if-then" rules (H. Leventhal et al., 1999). The last piece of a complex theoretical puzzle had been found. Participants had a codified set of rules that determined their actions so that the overarching theoretical category was: different groups had different responses to heart disease symptoms.

The final categories making up this theory were split into the initial context and the intervening conditions and consequences. Categories included in the initial context were: symptom descriptions, perceptions, expectations which became 'people perceive symptoms in different ways' with two subcategories: describing chest pain and not recognising it as heart related and describing symptoms in vague terms. The categories: lack of knowledge, knowledge, expectations and fears became 'people have different expectations about symptoms' with three subcategories: beliefs about symptoms, symptoms arouse anxiety in different ways and confusion and uncertainty about symptoms. Two sets of categories made up the intervening conditions. First, the categories: maintaining the status quo (women enduring pain), holding the fort (men protecting others from their pain) became 'people endure symptoms in different ways'. Secondly, the categories: communication, seek reassurance, obtaining

reassurance, general practitioners, and personal knowledge became ‘people obtain reassurance in different ways’. The last categories were related to participants’ actions, which created consequences resulting from their symptom experiences. These categories were: permissible and sanctioned actions and learning new codes that became ‘people take action in different ways’. The model of response to heart disease symptoms (Creswell, 1998) on page 207 provides a visual representation of the concepts that form the theory.

#### *Assessing the trustworthiness of the data analysis*

During the data analysis the researcher set out to test the trustworthiness of the findings. A consistency check is “having another coder take the category descriptions and find the text which belongs in those categories” (Thomas, 2003). Two colleagues who did not know anything about the study were chosen to review the transcripts in conjunction with the research objectives and independent category descriptions. One person was chosen for her expertise in sociology and lengthy experience with people who were recovering from heart disease. The second person was from a psychological background with a strong clinical background of behavioural interventions for heart patients, had expertise in question formation and analysis of data. Two sets of independent parallel coding were conducted. Initially the independent coders were given the research objectives and a section of raw text and asked to create categories. The second set of categories was compared with the researcher’s categories to find similarities and differences between the category sets. The two sets of categories were combined. Secondly, a check was carried out on the clarity of the researcher’s categories. They were each given a set of descriptions for the main categories and instructed to examine and code the raw data for conversations matching the category labels. The raw text contained selections of text initially coded by the researcher. Then the researcher provided text that had not been coded and the coders were asked to “assign sections of new text into the initial categories” (Thomas, 2003). These colleagues did not discuss the data amongst themselves. Separate feedback was given to the researcher. The two sets of categories were discussed with a supervisor and the data was judged to be consistent.

### *Consultation with stakeholders*

Three stakeholder checks were used to assess the credibility of the data. 1) During the process of interviewing the researcher would ask participants to verify interpretations of data gathered in the previous interviews. An example of this process is when interviews were completed the researcher would check the relationship between women's pain and symptom experiences and their experience of pain in childbirth. 2) A copy of the transcript was sent to each participant. All participants (except three who had died post interview) returned their transcripts together with comments about the interview text. These comments were included and the text was altered according to the participants' feedback. In each of the three cases where participants had died after their interviews, relatives had contacted the researcher after receiving a copy of a transcript. A letter of condolence was sent to each spouse.

The ethics application included a plan for follow up counselling sessions should participants or their families become distressed about events surrounding the illness. The researcher provided counselling for one spouse whose partner had suddenly died after his heart attack at a relatively young age. The counselling sessions took place after the interview transcript had been sent to the participant. The adolescent children of the deceased participant appreciated the interview transcript. The children believed that it provided a precious, personal record of their father's heart attack story. The widow considered the transcript to be an important piece of her spouse's history to be read and shared as the family grieved. 3) Other stakeholder checks were done through informal conversations with a woman cardiologist, general practitioners and Maori advisors. A copy of preliminary results was disseminated to participants and health professionals involved in the study.

### *Comparing the field data with the literature*

At this point the researcher thought that the data was not revealing anything significant. The researcher reviewed the literature to check the emerging findings. These findings sharply contrasted with the literature studies (Bullen, 1997; Doggen et al., 1993) where women were blamed for the dire consequences that arose from delays to seek medical care (people weren't in time to get treatment or people died). The first breakthrough was the everyday language. This language was so important because it was nothing like medical jargon. The women were describing their

symptoms within their socially constructed roles. The researcher reviewed studies with common and uncommon symptoms in acute coronary syndrome, which showed that women may present with atypical symptoms (Goldberg et al., 1998; H. Meischke et al., 1998). The data revealed distinct differences between symptom descriptions and perceptions of symptoms of women and men participants. The data also revealed the differences between medical jargon for labelling symptoms and symptom descriptions used by participants, which related to the context of their daily lives.

## **Summary**

This chapter has described the methodology for the theory development of 'Recognising women's responses to heart disease symptoms: different groups respond in different ways' from the transcripts. The study design, aims and objectives were explained. The community consultation process and steps taken to gain ethical approval were outlined. The sampling frame consisted of Maori and European participants aged between 45 and 85 years with a diagnosis of angina, high risk of heart attack or a previous AMI. Information about the study was distributed to 35 participants who met the inclusion criteria. Thirty-four people decided to participate. A profile of participants was purposefully selected using the theoretical sampling technique and was presented in a data collection flow chart (See appendix L). The data collection procedures used two semi-structured interview schedules. The study interview schedules, interview process and procedures for administering the interview were explained. The process of data coding and categorisation as interpreted by the researcher was conducted with the computer software programme. The data analysis and writing included theoretical decisions about categories and coding as well as an explanation of the strategies for building up the data set. Strategies to ensure the trustworthiness of the data were explained. This chapter sets the scene for the four results chapters. The following chapters report results from the study findings: Chapter Six reports findings from the initial context of participant's symptom experiences. Chapter Seven outlines the findings from three Maori key informants. Chapter Eight and Chapter Nine report the findings from the intervening conditions when participants were making decisions about their symptoms and the conditions that influenced them.

## CHAPTER VI: RESULTS: SYMPTOM PERCEPTIONS

*Women are diverse, durable fantastic survivors who have learned to adapt in circumstances so inhospitable that men have never even risked entering them.*

Judith Aitken, Chief Executive (*Quotable New Zealand women*, 1994)

### Overview

There are four results chapters. Chapter Six contains the themes and findings that were used to begin development of the emerging theory. Chapter Seven reports the findings from three Maori informants that were used as a backdrop to inform the findings from Maori participants. Chapter Eight covers how participants endure their symptoms before obtaining reassurance from their people in their surrounding environment. Chapter Nine shows the variety of ways that participants sought reassurance for distressing symptoms and some of the coping actions used to relieve symptoms. A summary of key findings precedes the theoretical model together with a discussion of the final two categories.

### Introduction

The overarching theme developed from the emerging theory is: 'Recognising women's responses to heart disease symptoms: Different groups respond in different ways'. The three main sections in this chapter are: Part One reports the delay times in care seeking for study participants. Part Two, which covers the category 'people perceive symptoms in different ways,' explains the differences in symptom perceptions and beliefs about the cause of symptoms among women, men, European and Maori. In Part Three, the category 'people have different expectations about symptoms' highlights participants' confusion about symptoms, how symptoms arouse anxiety in different ways and confusion about contemporary viral illnesses. At the end of three parts there is a discussion of findings and theory development linked to delay times, rules governing relationships, symptom interpretations, and European and Maori women's difficulties recognising heart disease symptoms. Then further discussion follows in relation to confusion about heart attack images, which includes communication problems between doctors and participants, stereotypical responses in

treatment interventions, confusion about contemporary health threats and public perceptions of emergency services. Then the chapter is summarised.

### **Part One: Delay times**

Surviving symptoms of heart disease is one process that is incorporated into the many activities that make up people's lives. The participants are coping with their heart disease symptoms on a continuous basis, whereas this research is a causal-consequence model where the findings are reported with a beginning and an end. For these participants, surviving the threat of angina or death from a heart attack is a significant part because through their stories they have entrusted the researcher with their individual coping strategies to relieve symptoms (survival codes). The title 'Recognising women's responses to heart disease symptoms: Different groups respond in different ways' replaces an earlier label 'preferences for dealing with pain or symptoms' that was too narrow to describe the complex survival processes. This theoretical code has emerged from the data provided by the participants in the initial context of their symptomatic episode.

The symptom descriptions, short or long delay times and mode of transport for seeking medical care are reported in tables six and seven. Theoretical categories include 'people perceive symptoms in different ways' and 'people have different expectations about their symptoms'. These categories are linked together to create the first part or initial context of the theoretical concept of 'Recognising women's responses to heart disease symptoms: Different groups respond in different ways'. The length of delay times related to participants' symptom interpretations and subsequent coping strategies to deal with distressing or acute symptoms are reported in tables six and seven.

As shown in Table 6.1 delay times from symptom onset to hospital admission taken from the medical records were: five participants (one European woman, three European men and one Maori man) delayed less than two hours (range 1 hour to 1 hour 30 minutes). In three cases an ambulance was summoned. One woman had collapsed and two men were experiencing chest discomfort or arm pain. One man consulted the general practitioner for a sore arm and chest discomfort which was

initially misdiagnosed as indigestion, an ambulance was summoned when the symptoms worsened. Six participants (two European women, two Maori women and two Maori men) delayed more than 2 hours (range 2 hours 30 minutes to 10 hours), one participant's admission time was not recorded and one participant waited approximately three weeks. Five participants consulted their general practitioner, two women were sent to hospital by ambulance from the medical clinic one man received a misdiagnosis and one woman had collapsed and was transported to hospital by ambulance.

As shown in Table 6.2, delay times from symptom onset until hospital arrival or attending a medical clinic showed that four participants (three European men and one Maori man) delayed less than 2 hours (range 1-2 hours). In two cases an ambulance was summoned, one man had collapsed the other man had difficulty breathing and the two other men drove to the medical clinic. Fourteen participants (three European women, three Maori women, six European men, and two Maori men) delayed more than two hours (range 4 to 24 hours and several days). One man was transported by ambulance to hospital after a delay of four hours, and thirteen participants drove to their local doctor. Three European women (one had delayed five hours and two had delayed twelve hours) received a misdiagnosis from their doctor after presenting with vague or atypical cardiac symptoms. When their symptoms became acute, emergency services were contacted and they were admitted to hospital. One woman was referred to a cardiologist. These times are taken from transcript records of the participants' recall of events and not validated by the clinic records.

### **Summary of delay times**

Delay times from symptom onset to hospital admission were: five participants delayed less than two hours (range 1 hour to 1 hour 30 minutes), and six participants delayed more than two hours (range 2 hours 30 minutes to 10 hours). Delay times from symptom onset until attending a medical clinic were: four participants delayed less than two hours (range 1 to 2 hours) and fourteen participants delayed more than two hours (range 4 to 24 hours). Hospital delay times show that five participants delayed less than two hours (range 1 hour to 1 hour 30 minutes). Six participants delayed more than 2 hours (range 2 hours 30 minutes to 10 hours). Six participants consulted a general practitioner rather than contacting emergency services, which

resulted in longer delays. Delay times in the community show that four participants delayed less than 2 hours before contacting their local medical clinic. Fourteen participants delayed more than 2 hours (range 4-24 hours and several days). Of the fourteen participants that delayed more than 2 hours, thirteen participants travelled by car to the clinic. Three participants presenting at their local doctor for heart disease symptoms were misdiagnosed. Only one participant was promptly referred to a cardiologist.

**Table 6.1: Delay times for participants admitted to hospital for a first acute myocardial infarction.**

<b>GENDER ETHNICITY HOSPITAL</b>	<b>SYMPTOM DESCRIPTIONS</b>	<b>SHORT DELAY &lt; 2 hours</b>	<b>LONG DELAY &gt; 2hours</b>	<b>TRANSPORT/ GENERAL PRACTITIONER</b>
Woman (E) Middlemore	Fatigue	1 hour		Ambulance
Man (E) Middlemore	Sore arm	1 hour 30 minutes		GP Ambulance (Misdiagnosis)
Man (E) Green Lane	Burning pain	1 hour		Ambulance
Man (E) Green Lane	A bit tight	1 hour		Ambulance
Man (M) Middlemore	Burning sensation in chest	1 hour		Ambulance
Woman(M) Middlemore	Chest tightness		2 hours 30 minutes	General Practitioner
Woman (E) Auckland	Chest tightness		3 hours	GP and Ambulance
Woman (E) Green Lane	Heavy feeling		3 hours	GP and Ambulance
Man (M) Green Lane	Chest ache		10 hours	General Practitioner
Woman (M) Green Lane	Vomiting and Diahorrea		Time not recorded	Ambulance
Man (M) Middlemore	Chest pain. Shortness of breath A little bit not too well		Approximately 3 weeks Time not recorded	General Practitioner (Misdiagnosis)

Ethnicity: (E) = European, (M) = Maori

**Table 6.2: Delay times for participants in the community.**

<b>GENDER CLINIC</b>	<b>SYMPTOM DESCRIPTIONS</b>	<b>SHORT DELAY &lt; 2hours</b>	<b>LONG DELAY &gt;4 hours</b>	<b>GENERAL PRACTITIONER/ TRANSPORT</b>
Man (E) South Auckland	Getting Short of Breath	1 hour		Ambulance
Man (M) West Auckland	Just went straight out	1 hour		Ambulance
Man (E) South Auckland	Blurred vision tightness	2 hours		Visited GP Car
Man (E) West Auckland	Burning across chest	2 hours		Visited GP Car
Man (E) West Auckland	Didn't have a pain. I felt things		4 hours	Ambulance
Woman (M) West Auckland	Short of Breath Heart flutters		4 hours	Visited GP Car
Woman (E) Central Auckland	Tired Electric shock		5 hours	Visited GP Car (Misdiagnosis) Ambulance
Man (M) West Auckland	Sharp pain like a swelling in the ribs, its like cramp		8 hours	Visited GP Car
Woman (M) South Auckland	Right across chest		12 hours	Visited GP Car
Woman (E) South Auckland	Didn't feel good Just felt blah		12 hours	Visited GP Car (Misdiagnosis) Ambulance
Woman (M) West Auckland	Sore heaviness		12 hours	Visited GP Car
Woman (E) South Auckland	Didn't feel well		12 hours	Visited GP (Misdiagnosis)
Woman (E) West Auckland	Squeezed both sides, the pressure		12 hours	Visited GP Car
Man (M) West Auckland	Blurred vision, floating feeling		12 hours	Visited GP Car
Woman (E) Central Auckland	Going down with flu		24 hours	Visited GP Ambulance
Man (E) Central Auckland	Soreness in the chest area		24 hours	Visited GP Car
Woman (E) West Auckland	Chest tightness		24 hours	Visited GP Car Referred to Cardiologist
Man (E) Central Auckland	Flu symptoms		Several Days	Visited GP Car

Ethnicity: (E) = European, (M) = Maori

## **Part Two: People perceive symptoms in different ways**

Whatever a person's socio-economic status may be in terms of comfortable living standards or economic deprivation people constantly act out patterns of daily survival. Some examples of survival patterns are continuing work or household tasks while

sleep deprived from tending a young child who wakes during the night, surviving financial deprivation through loss of employment, or surviving sickness whether it is the individual or a close family member. These determined efforts under difficulties (Fowler & Fowler, 1962) are bound by traditional sets of rules (Argyle & Henderson, 1985).

Survival from the life threatening onset of heart disease symptoms is a scenario that illustrates the different perceptions and rules for behaviour between women, men, European and Maori. The rules governing relationships are activated when survival strategies are utilised, they are translated into conscious or unconscious codes. Women's survival strategies have been based on codes of endurance whereas men respond to codes of honour. Maori behaviour is bound by the survival codes of tapu and noa. The theoretical underpinnings of rules for relationships and survival codes are discussed after the findings in the first category. Initially the symptom descriptions will be discussed and in the following section there is a discussion covering expectations and beliefs about symptoms.

The first key to these codes was the mundane way that participants described and behaved when experiencing their symptoms. Study participants used plain or everyday language to describe their symptoms and the majority of participants did not recognise their symptoms as heart related. Some of the symptom descriptions were vague, whispered, or referred to in Maori language. Symptom descriptions are linked to people's perceptions. Symptoms are perceived differently according to gender and cultural constructions. The descriptions were bound up with people's previous symptom experiences, and symbolic meanings were attached to symptom perceptions.

The Oxford Dictionary describes a symptom as:

Perceptible change in the body or its function indicating injury or disease. A sign or token of the existence of something (Fowler & Fowler, 1962, p. 1083).

An acknowledgement of a sign or an existing bodily sensation is shrouded with the expectations of the traditional roles of women, men and Maori. When a symptom is acknowledged specific, learned role behaviours direct people's responses. None of

the women believed that they were having serious symptoms such as those associated with a heart attack. Women used their prior pain experiences and health knowledge, which is different to men, when exercising judgement about their health status. The findings for the categories people perceive symptoms in different ways and people have different expectations about their symptoms are discussed under specific ways that demonstrate how each group of participants responded to their symptom experiences. First of all, symptom perceptions are explained in the concept that defines how people perceive symptoms in different ways. These responses to symptoms were carried out as a normal part of participants' daily living activities and the category labels reflect their commonsense models of illness. Participants' symptom perceptions were expressed in 'run of the mill' terms in plain language so that the symptom experiences were regarded as just a normal part of everyday life. The categories describing chest pain and not recognising it as heart related and describing symptoms in vague ways reflect commonplace terms which capture the meanings of these episodes according to participants' commonsense perceptions. The following section commences with the mundane sounding but significant ways of describing symptoms.

#### *Notes about the participants' dialogue*

Participant dialogue is in italics, the words describing symptoms descriptions are underlined to emphasise them, if words are spoken loudly they are underlined, pauses in conversations are marked with dots and the researcher's notes are placed in brackets, names and places have been omitted.

#### ***Describing chest pain and not recognising it as heart related***

This category refers to the common labels people give to identify the bodily sensations or pain experiences. A further meaning in this category can be described as the participants were describing serious symptoms of either angina or a heart attack but their actual descriptions were related to their beliefs that the symptoms were caused by something other than heart disease. The third meaning in this category is that participants were not recognising their symptom experiences as potentially life-threatening. The consequences of not possessing knowledge about heart attack or angina symptoms meant that participants had lengthy delays before they sought medical assistance.

The following symptom descriptions are from European and Maori women followed by European and Maori men's symptom experiences. Three European women described their symptoms in non-dramatic terms. They used plain everyday language to communicate their body sensations. The symptom descriptions are highlighted to emphasise the exact wording. The descriptions are 'original' in that they have not been tampered with or re-phrased by health professionals. Two European women described tightness in the chest area while the other woman experienced a heavy feeling in the centre of her chest.

This woman was at home and in the presence of a woman doing her housework when she had her first angina attack. She had been recently widowed. Her husband had been admitted to hospital with severe heart disease and had died in hospital.

*I didn't need hospital care I could just feel it coming on and comes on as though I am being squeezed from both sides the pressure. (European woman, 75 years - Retired)*

Her angina symptoms persisted over a period of fourteen years. She was admitted to hospital for an angiogram test, but was not given one. (An angiogram is a procedure where radioactive dye is inserted through a catheter tube in the groin, which shows any blockages in the heart arteries which are caused by, build up of fatty substances called atherosclerotic plaques).

*I got there and they decided not to do it. .... Then they said we think you should go home and we will call you when we want you and that was the finish. I never heard anything more (European woman, 75 years - Retired)*

In the past her GP had treated her for anxiety and had prescribed nitro lingual spray for angina symptoms. This woman did not relate the pressure on her chest with having a heart attack. She believed that she could control her symptoms with self-treatment at home. At the time of the interview she explained that she had remarried, was very happy and her angina episodes had virtually disappeared. She perceived that having angina attacks less frequently meant that she would not be admitted to hospital with a heart attack.

This woman led a busy life, participating in the workforce, working in the family home, caring for children and maintaining a large garden on a rural lifestyle block. She experienced her first angina episode after a strenuous day in her garden. She thought her symptoms were caused by an allergy.

*Only when I was mowing the lawns. .... I felt just a slight tightness in the chest. We had moved out into the country I thought it might have been pollen or something like that affecting the chest area. .... I was very uptight. Well I hadn't been sleeping for a long time since the beginning of menopause and I think this was the build up because it happened in the morning. I woke up and it had happened. I said to (the GP) I think a lot of it is because I'm stressing out at night because I'm not sleeping and this was making my blood pressure go sky high....I was very scared (European woman, 57 years - Clerk)*

Distressing symptoms related to the menopause had preceded her angina symptoms. She explained that she was not sleeping well, very anxious and upset and her blood pressure had been high. The GP had not placed her on anti-hypertensive medication but was monitoring her blood pressure regularly. She was very frightened about her angina symptoms.

The third European woman had pursued a busy lifestyle as a director in her husband's business, playing sport regularly and attending to the needs of her married children and the grandchildren when they visited from overseas.

*It was a heavy feeling in the middle of my chest. I put it down to stress; I didn't think it was anything to do with heart. .... I suppose it does affect you. .... I think we might be retiring a bit sooner. (European woman, 58 years – Company Director)*

Her symptoms were mild at the beginning of her acute episode that led to an admission to hospital for an AMI. She stayed in bed resting, for approximately 90 minutes, then the symptoms increased in severity to the point where her husband contacted the GP. She believed that her symptoms were caused by a stressful

lifestyle. The GP advised her husband to ring for the ambulance when she was not able to get out of bed.

When describing the symptoms these women participants did not converse in terms that are familiar to the medical profession, *slight tightness in the chest* where signs and symptoms are clearly labelled and related to specific diagnoses such as chest pain or chest discomfort. These women did not perceive that their symptoms emanated from the heart. They reported sensations in the chest area and they perceived it as a mild symptom, *I didn't need hospital care I could just feel it coming on* which they believed they could control through self-treatment (such as resting) until the symptoms were relieved. Two women believed that the symptoms were caused by their lifestyle, *I'm stressing out at night and I put it down to stress*. Also one woman described her active life and she believed that her symptoms were caused by overexertion from mowing the lawn, *when I was mowing the lawns*. All three European women described classic heart attack symptoms but they did not perceive that their symptoms required urgent medical attention.

Three Maori women described their symptoms, as heaviness, tightness or discomfort, which was similar to the European women. But their symptom experiences were imbued with Maori cultural connotations and therefore subtly different. It was of crucial importance that a Maori woman conducted these interviews, with the Maori women participants. The strategy of matching the ethnicity of both interviewer and interviewee not only allowed these participants to feel more comfortable about sharing their stories but also allowed them to communicate in familiar Maori ways. The richness of the descriptions is demonstrated by the intertwining of the Maori and English languages. The interview process reveals that Maori women responded more to the word 'tohu' (sign) than to the European word symptoms. Even with the interviewer giving permission for the participant to express their symptoms in a Maori cultural context, people were very reluctant to mention their symptoms.

During the interview process the interviewer used several prompts which can be seen in the first text example, after a karakia (prayer) first she hesitantly asked about symptoms, then she used the Maori word for symptoms, then she asked about bodily sensations. Three Maori women described constriction in the chest area; their

reluctance to discuss the symptoms is shown by the indistinct replies and shyness (whakama) around the symptom descriptions. The pattern of indistinct replies is also an indication of personal apprehension about symptom consequences. This apprehension stems both from their self-identification as Maori and customary rules for maintaining health and wellbeing. The use of concepts such as tapu (unsafe or risky) and noa (safe) are the traditional Maori ways that Maori make reference to signs and symptoms of ill health. The word 'tohu' (sign) encapsulates the way Maori communicate about ill health. This woman had visited a GP (in a rural area) for asthma symptoms approximately eight years ago and learned that she had an enlarged heart. She did not recognise that her symptoms may have been angina caused by her heart. Interviewer: Do you have any, any symptoms, any tohu? (sign) Any pain?

*Yes I did, down there (indistinct) Around the chest ay? (shyness or whakama)  
Ah, yeah. That's what made me go to the doctors, is that, you know, you got sore heavy, (indistinct) and then it's painful too, you know. . I could feel it, the pain. But when I rub it, I, it seems to help, you know. ....and then I hope, oh, it might be, what d'you call it, wind or something... (Maori woman, 72 years - Retired and Maori Warden)*

While at home, this woman was overcome with painful, distressing, angina symptoms. She told her husband who got her to contact the Practice Nurse and then he drove her to the clinic. This woman was familiar with local Maori health providers. She experienced a positive relationship with clinic staff that checked her out thoroughly and she had been encouraged not to put up with painful symptoms.

*Tight in the chest. Right across. Didn't know where (indistinct) I went and lay down and I didn't know how to lie, whether the side or back or the other side. No, I think that was the very first time. I've had pleurisy but (indistinct) Couldn't work it out. I just knew it wasn't pleurisy .... when he saw my face was white. (indistinct). (Maori woman, 64 years - Sickness Beneficiary)*

This woman described her chest pain as discomfort that occurred when she was taking a shower. At first she believed that she had indigestion. When the symptoms persisted she assumed it was a heart attack and summoned help.

*Well I'd just finished having my shower...and I bent over to dry my legs, you know, I bent over to dry my bottom half (shy response to the body or whakama) and then I felt a bit of a discomfort in the chest. That, it was focussed right in the centre of my chest and I knew that it was more than an attack of heartburn because in my mind my guess was that it was probably a heart attack. (Maori woman, 66 years – Retired)*

The Maori interviewer picked up the cultural unspoken cues that impacted on Maori reluctance to discuss symptoms. As a senior Maori woman she was able to draw out participants' symptom experiences and place them in a cultural context. By matching the ethnic background of interviewer and participants the interview took place in a way that was comfortable for Maori women. The process of reciting a karakia placed these participants in a safety zone where their shyness about discussing symptoms around the breast area was accepted by the interviewer as an appropriate cultural response and not construed as ignorance. One woman believed that her pain was caused by wind, *what d'you call it, wind or something* and the other woman simply did not know what was causing her symptoms and her previous experience of pleurisy. *I've had pleurisy*, was the closest match to her heart symptoms. Only one woman recognised belatedly that her pain was heart related, *it was probably a heart attack* and potentially serious.

One European man described his chest pain in a similar manner to the other six women. This man had a highly stressful job as a manager in the media industry. He had been walking to the bus stop on his way to work when he experienced AMI symptoms and was admitted to hospital.

*Well not that I am conscious of. Occasionally I might get that you know heart burn it might get a bit tight and it might just come and go in a matter of minutes. Probably more like indigestion. No real symptoms. (European man, 48 years - Manager)*

When he reflected on his symptom experience it was described as a tight feeling, which caused intermittent discomfort. He believed that it was indigestion and

perceived that the bodily sensations were not real symptoms therefore he got on the bus and continued on his way to work.

Maori men responded in the same way as Maori women when it came to discussing their symptoms. A karakia was conducted before the interview commenced. Maori and English language became intertwined and the actual symptoms were spoken in whispered tones. The words that the Maori interviewer used (nga tohu or sign) triggered meaning for Maori men. Using Maori terminology made it easier for Maori men to discuss their symptoms. Shyness or whakama was an issue, which was indicated when the tape was turned on and off. One man described his angina episode as sharp pains emanating from the ribs or chest that he compared to having cramp in his calf muscles. Some of the symptoms were related to levels of physical activity and the values or mana of being able to carry out their manual work whilst still experiencing severe pain.

*Largely the sharp pain on one side and on the left side of the chest. Very sharp pain, like a swelling through the ribs. As if to say you've got cramp. It's like cramp. It always starts strong, starts in the rib, through the rib cage and it stays there for a good, ah, ten minutes, ah, ten seconds, and disappears. It comes on again about another half hour. Yeah, that's the first sign, a sharp pain right in the centre of the chest. I'm sitting down, pulling myself forward and hold myself down like that. (indistinct) Still active. Right up to, I got to Sergeant (indistinct) (Maori man, 61 years – Sickness Beneficiary)*

He explained that he was physically active in the past and had attained the rank of Sergeant in the army.

*Oh, a bit of a stabbing pains, you know. It went and settled, toku ngakau (my heart), and they called it angina and they found out, oh, they tried that other stuff (indistinct). Stressed out mo tau iwi, stressed out mahi I ra. Was a bit of a, I thought it was a heartburn, it was starting to mamae (pain) I thought I had a bit of heartburn there. Had tiki toku rata (fetched my doctor) (Maori man, 57 years – Unemployed)*

He believed that the death of his first wife and two subsequent broken marriages had affected his physical and mental health. Another man described his pain with a Maori term, a *mamae* (pain). He was at a shopping centre and thought it was caused by indigestion so he visited his GP.

### **Summary of symptom descriptions**

Initially, participants did not recognise that their chest pain was heart related and possibly serious. This category identified what participants believed was the cause of their symptoms that was linked to the way symptoms were described. This category only reports the participants' beliefs about symptoms at the time. It does not address the legacy of beliefs that imbue our perceptions about hearts as they occupy a place of special emotional significance in people's lives. Seven participants believed that their symptoms were not related to heart disease. Four European women described the cause of their symptoms as: *stress, a pinched nerve, flu* or *allergy*. Three Maori women believed, *indigestion, wind* or *pleurisy*, while three European men believed the cause to be, *flu, heartburn* or *indigestion*, and two Maori men attributed their symptoms to, *heartburn* or *indigestion*. Women reported a more varied range of beliefs than men.

Two women had experienced angina episodes. One woman had suffered from angina for fourteen years, did not undergo further hospital tests so she thought, *I didn't need hospital care*, and did not view her angina symptoms as life threatening. One woman had been experiencing distressing menopausal symptoms, and had been monitored for high blood pressure which she attributed to two causes: *because I'm stressing out at night, because I'm not sleeping and this was making my blood pressure go sky high*. This woman had not been prescribed blood pressure medication. When her angina episodes occurred she believed they were an allergy and was very frightened, *I was very scared* about her diagnosis. Maori women with angina described it as, *you got sore heavy, Tight in the chest*, but attributed the pain to wind or pleurisy. Two women, *I didn't think it was anything to do with heart, I felt bit of a discomfort in the chest* and three men suffering, *No real symptoms, mamae, very sharp pain*, acute symptoms of an AMI did not recognise that their symptoms required urgent medical attention.

### *Describing symptoms in vague ways*

This category label means that symptoms were described in unclear or indistinct terms, which contributed to delays in diagnosing heart disease. Three European women described vague symptoms such as not feeling very well, under the weather or coming down with a flu virus. It is this vague or ordinary terminology for symptoms descriptions that is an important key to unlock what people will do in response to their symptoms. All of these women did not relate their symptoms to heart attack messages. These women did not perceive their symptoms as serious. The symptoms were intermittent with low levels of discomfort and were not breaking through with enough pain that would interfere with their daily activities. This woman had been the hostess for a luncheon party.

*I was feeling very, very tired. I was so tired I could hardly finish my hostessing you know. She went home about 2.00 o'clock. (European woman, 78 years – Retired)*

Most of the time women were discussing their discomfort in normal, conversational tones, which indicated that they were not overly upset or worried about their state of health at that point in time. One woman woke up with painful symptoms and stated in a louder voice that she felt unwell. She explained that the cause of her discomfort was her arm. She got up and went to work then was driven to hospital that night. Another woman continued to feel run down but carried out her voluntary work at a private hospital for older people. She suffered acute symptoms while there and an ambulance was summoned.

*It was the morning at home and I didn't feel goood at all just blah. Well I thought that I had been sleeping the wrong way. You know how you crush your arm sometimes when you are sleeping and get a pinched nerve. (European woman, 76 years - Retired)*

*I wasn't feeling very well at all. I thought I was going down with the flu Actually, I didn't have a cold or anything; I felt absolutely run down. (European woman, 71 years – Retired)*

When men reported their symptoms they were reluctant to discuss them. Three men described symptoms that were more vague and one man described a feeling of being just unwell. Men did not recognise their symptoms as heart related. It took the interviewer some time to make them feel comfortable enough to admit to symptoms in the first place. This man visited his GP with flu like symptoms after resting at home and being cared for by his wife a few days. He was diagnosed with angina.

*The symptoms, which brought me to the clinic in the first place. Um, I had the flu or something like that, when I get a cold it is usually a heavy one as a rule.*  
(European man, Retired –73 years)

One man had problems with his vision and visited his GP. He was later admitted to hospital and underwent an urgent angioplasty. (A surgical procedure where a catheter is inserted into the groin with an umbrella-like instrument attached to it that applies pressure to the artery wall and unblocks it.)

*It was round about, oh,.. And, ah, it was floating around but I looked up around in the mall and I couldn't see them so I went to the doctor.* (Maori man, 57 years - Unemployed)

The third man had suffered from some sensations in his chest and indigestion. He was tested and admitted to hospital with an AMI.

*It was in my chest - It was like as if I had um indigestion. And um I told them it was indigestion and then they, they gave me, they gave me some white fluid to drink.....and um told them that I had pains and they put all the, all the wires on me and they still couldn't find out what was wrong. So they put me in an ambulance and sent me here (Hospital).* (Maori man, 54 years- Labourer)

Most of the men did not raise their voices when describing their symptoms. Men used matter of fact language to describe their symptoms and their conversation style on the surface conveyed less description about feelings or reference to emotions than the women.

The vagueness or ordinary sounding symptom descriptions when presenting at GP clinics often led to hospital admission for life threatening heart conditions. *I was very, very tired, not feeling not good just blah, I wasn't feeling very well at all, the flu or something like that, it was floating around I couldn't see, like as if I had um indigestion.* Vague symptom descriptions led to significant delays in reaching hospital for appropriate treatment.

### **Summary**

Women reported a greater variety of beliefs about symptoms than men. European and Maori women thought that angina symptoms were not life threatening because they did not experience severe pain. European and Maori men experienced heart attack symptoms but they did not know that their symptoms required emergency medical care. Vague symptom descriptions increased the likelihood of prolonged delays in reaching medical care.

### **Part Three: People have different expectations about symptoms**

When participants are experiencing symptoms they expect some consequences to arise from the symptoms both before they seek treatment and after they treat themselves or seek medical assistance. The dictionary defines an expectation as:

Anticipation about the probability of something happening (Fowler & Fowler, 1962, p. 37).

This category label means that participants expected that their symptoms were caused by something that they were familiar with such as heartburn, or indigestion. The label also means that when there was uncertainty about the origin of symptoms both participants' and doctors' expectations about symptoms became mixed up or confused. In a number of cases when participants were describing their symptoms they explained what they thought had caused the symptoms. The discussion of participants' expectations shows how personal expectations are intertwined with emotional responses. When participants' anxieties about distressing symptoms were not relieved they scanned their social environment searching for reasons to explain the cause of symptoms. The categories, 'expectations about symptoms can arouse

anxiety in different ways’, ‘confusion and uncertainty about symptoms’ and ‘lack of knowledge about thrombolytic therapy’ provide a snapshot of just how frightening heart disease symptoms can be to an individual who had never had this experience before. These fears are something that health professionals tend to overlook because they are constantly dealing with life threatening symptoms on a daily basis and these symptom presentations become routine.

***Expectations about symptoms can arouse anxiety in different ways***

Most participants expressed fears and anxiety about their symptoms. The sources of participants’ anxieties were verbalised in several ways. After hearing a diagnosis of angina from her GP one woman was very scared because she did not know about the consequences of her symptoms.

*I was very scared. I didn't really know what angina was and didn't really know what to expect. (European woman, 57 years - Clerk)*

This man was on his way to work on the bus when his symptoms became so severe he asked for help. He feared losing control, being anonymous and not able to communicate with family or bystanders witnessing his acute symptoms if he was dying.

*I never lost my reasoning. It might have been hard to talk to people because of the shortness of the breath but I could remember phone numbers.... thinking at the moment I am an anonymous person in an ambulance and when they ask me who I am I had better tell them. (European man, 48 years - Manager)*

Two Maori men voiced fears about the loss of their livelihood after surviving their first heart attack. Maori have more financial responsibilities for supporting large whanau groups and they are more likely to be employed in labour intensive, low paid jobs like truck driving.

*The top fellow was getting a bit worried with me driving and he didn't want to take my licence off me because it's too much of a hassle trying to get a licence back to me, costs money. (Maori man, 52 years – Self Employed)*

*I, I, I, I am worried. Yeah, I'm worried about, you know, I don't want to lose my house. Because I didn't take out any insurance on my, what do they call it? He was a worker that worked in the tunnels all, most of his young life, down in the South Island, ...and then just out of the blue he rang my brother in (town) and said he wanted to come home.....he was well, he was looking really well. So we took him back to my brother's house in (town) and then two days later he passed away. (Maori man, 54 years - Labourer)*

One of these men revealed a grim reality for Maori whanau in terms of their knowledge that many whanau members are employed in low paid jobs that require hard, physical labour, *He was a worker*, and their low socio-economic status contributes to poor health that they die, *two days later he passed away*, earlier than Europeans.

### ***Confusion and uncertainty about symptoms***

Confusion and uncertainty are defined as: “confuse, to mix up in the mind”: and “uncertain, not certainly known” (Fowler & Fowler, 1962, p. 198). This category label means that participants did not know what caused their symptoms and therefore did not know what to expect during a symptom episode. It also means that there were gaps between both doctors’ and participants’ expectations about symptoms. Another meaning is that both doctors and participants became mixed up as to the cause of symptoms. This woman recalled her training in first aid and used her personal pain experience from doing gardening work and comparing it to what she knew about heart attacks. She also touched on her history as a New Zealand woman who had worked on farms with little assistance from men many of whom were overseas fighting during World War II. In the introductory stage pre-interview the majority of women participants would say that they were more used to bearing pain than men. It was always discussed in a humorous way like an “in-joke” with conversations between women.

*Only because I had been trained in first aid and there is a difference between pain from gardening work – tomboy work as I call it – boys' jobs – and the pains you get with that type of job. You could swing an axe into a block of wood and there will be a*

*knot and it will jar and it will jar your chest but that is just a jar pain but the intense pain of the heart attack was intense. You have got to have immediate help. Well I just thought .. It was the cough associated with it earlier that put me off. I thought I was getting some virus or something. I won't be mistaken again not after what followed.* (European woman, 75 years – Retired)

Our contemporary exposure in health messages (often conveyed in the media) to the concept of viruses, colds and coughs which require rest and fluids (alluded to in this dialogue) rather than visiting a doctor - added to the confusion about this woman's symptoms. She had experienced episodes of fatigue and pain prior to the acute symptom episode, which had subsequently occurred suddenly.

This man had been treated for a stomach ulcer and he went to the general practitioner for symptoms that he expected to be indigestion, the doctor confirmed his expectations by agreeing that it was indigestion. The dynamics of the communication between patient and doctor can only be cause for speculation, as they occur in private consultations. But from the comparisons of symptom descriptions earlier (see Table 9.1 and 9.2) it can be illustrated that there are a myriad of miscommunications and expectations manifested in doctor-patient consultations.

*No didn't think it was the ulcer thought it was the heartburn. Well it was obvious I thought it was heartburn that's what the doctor said previously that's what it was.* (European man, 46 years – Mechanic)

This man described the gap between professional expectations about symptoms and people's symptom expectations. The concept of heart attack symptoms had never entered his head, he didn't know what to expect so he only called for help when the symptoms rendered him unable to continue on his way to work.

*I'd say you were clairvoyant. No you mean a couple of days before? I wouldn't honestly have been able to describe them because I've never been educated as to what a heart attack feels like.* (European man, 48 years - Manager)

A man who had been recently widowed was reluctant to discuss his symptoms. He referred to his knowledge of friends' angina symptoms when explaining his expectations of heart attack symptoms. His experience was similar to the previous participants' where he did not know what to expect with heart attack symptoms and he downplayed his experience with angina symptoms. His expectation was that his doctor would diagnose his symptoms as angina.

*I've had friends with angina, you know, some serious and some just mild – you know. I have never seen anyone with a bad angina attack so I wouldn't know. Well the same thing, a terrible pain in the chest. ....about medical things;... I didn't know I had had one. I felt no pain or nothin'. (European man, 80 years – Retired)*

The following conversations with women show two different expectations. The first woman had experienced mild angina symptoms and her anxiety level was very high. She was confused about what had caused her symptoms. Her confusion was exacerbated by her limited knowledge of heart attack risk factors. Her doctor had not prescribed anti-hypertensive medication and the doctor considered that her high blood pressure was caused by anxiety. This excerpt showed that she was very frightened about her symptoms.

*No never ever. It really freaked me out, ..... When (the doctor) started managing my blood pressure, the top one was quite high and he said that could be stress, because it usually is the top one. Anyway he didn't give me any medication for it because he said obviously there was more going on in my head; perhaps I was worrying subconsciously about it. (European woman, 57 years – Clerk)*

*I suppose I didn't think it was anything very bad. Because it was so totally out of the blue really. (European woman, 58 years - Company Director)*

While the other woman who experienced a sudden heart attack did not expect to have major health consequences, she expected her husband to have a heart attack because

the business was stressful, but it did not occur to her that she was at risk although she referred to herself, as, *I get most het up*.

*I would have thought no risk; I would have possibly thought my husband had more risk..... he almost thrives on that sort of stress whereas I get most het up about it I suppose that is the difference.* (European woman, 58 years - Company Director)

This man's comments about symptoms epitomise common expectations about heart attacks.

*A lot of people you talk to that had have had them. They don't remember because they just out cold. But that's what I would have expected I had a heart attack a sharp jabbing pain in the heart area. And unconscious.* (European man, 46 years - Mechanic)

Symptoms can cause confusion in both doctors and participants. Some of the confusion stems from media messages about viruses that are often intangible because they may have a short symptom span. Or dramatic messages about heart attacks, *just out cold*. Doctors can contribute to the confusion if they habitually treat someone for a single condition such as a *stomach ulcer*, which may result in overlooking symptoms caused by something else. One participant felt *freaky* and experienced high levels of anxiety that may have contributed to her confusion. Symptom experiences that cause uncertainty contribute to care-seeking delays.

### ***Lack of knowledge about thrombolytic therapy***

This category describes what participants did not know about the hospital treatment to limit damage to the heart muscle after a heart attack. One of the interview questions was designed to find out if people knew about thrombolytic therapy treatment and if so did it affect their expectations about treatment. The interview question was: Do you know of any medicine that makes a heart attack smaller?

*No. I know of clot busting things now, which I had never heard of before but I don't know. Oh beta-blockers I've heard about since that reduces it by 20%. (European man, 64 years - Chief Executive)*

*Not the actual heart attack itself but you could probably have a preventative type medicine... but the heart attack itself, no. (European woman, 73 years – Retired)*

*No, actual medication, like take a pill for it. No I don't. I've got so used to taking the nitro lingual spray. (European man, 69 years – Model)*

Only one participant was able to mention clot-busting drugs, other participants became confused about their other medications such as the nitro lingual spray. Two European participants mentioned aspirin as a preventative medication against heart attacks. All of the Maori participants did not know about 'clot busting' drugs.

Lack of knowledge or partial knowledge about angina, heart attacks, or thrombolytic therapy or risk factors adds to confused or uncertain expectations about the consequences of the symptoms. Patients have expectations that their doctors will listen carefully to their symptom descriptions and they expect an accurate diagnosis. Health warnings about viruses and over use of antibiotics add further to the confusion. Participants' worldviews do not include accurate expectations about heart attack symptoms.

### **Summary**

The delay times for participants in the hospital and community settings symptom descriptions have been reported and summarised. Participants' perceptions about symptoms were identified for women, men and Maori. The symptom descriptions have been described and the differences in language between each of the four groups have been identified. Participants had difficulties recognising their symptoms as heart related and those participants who described vague symptoms experienced lengthy delays before receiving appropriate medical help. Participants' expectations about symptoms were a source of confusion and uncertainty. Participants' showed that they lacked knowledge about the benefits of thrombolytic therapy.

## **Discussion**

This section has two parts and it discusses the findings from the two categories ‘people perceive symptoms in different ways’ and ‘people have different expectations about symptoms’ that have been reported in this chapter. The first part is about delay times, the second people’s symptom perceptions, while the third part covers people’s symptom expectations.

### **Delay times**

Recent analysis of delay times from the GUSTO-I and GUSTO II randomised trials (Gibler et al., 2002) measuring the effects of Fibrinolytic therapy in 27,498 patients showed that time to arrival at hospital has not diminished in seven years (averaging 84 minutes). Prolonged delay times in the community show that we need to focus more on the primary health care sector in order to promote better heart attack responses located in local communities. It would appear that more effort to provide and institute pre-thrombolysis units as established in Sweden where the delay to receive thrombolytic therapy was reduced by 58 and 56 mins in both urban and rural regions (Svensson et al., 2003).

### **Rules governing relationships**

Participants’ rules or codes of survival that govern relationships during a health crisis are important aspects of care seeking that require more attention from researchers. Code means a set of rules on any subject or the prevalent morality of society. The word survive means continue to live or exist. Survival is the process of natural selection or survival of the fittest (M. Durie, 1994; Fowler & Fowler, 1962). The process of survival is continuous and never-ending with unspoken rules that are handed down through generations. They are continuous whereas the basis for this research is a causal-consequence model where the findings are reported with a beginning and an end. Survival processes underpin our daily lives and differ according to gender and culture.

According to Durie (1994) the concepts of tapu and noa are codes for survival in Maori society. This set of unwritten regulations has three parts: tapu symbolises risk,

noa denotes safety and rahui means off limits. The codes have two broad aims: survival of future generations by adaptation to the environment and developing a guide for social interaction. In practical terms they were subsumed into a spiritual code for living. When the missionaries arrived to convert the Maori to Christianity they applied their own labels to the Maori codes. Tapu was denoted as sacred and noa was termed profane. In Maori society, parts of the body were tapu: the head, genitalia and the heart. The early Europeans, who colonised the land, applied a single meaning to these complex terms. It makes for commonsense knowledge that Maori had their own survival codes and knew what was safe behaviour and what behaviour was risky. Tapu can be permanent or intermittent. It is applied to people, events or social relationships. By historically misconstruing the terms of tapu and noa they have been overlooked as keys to unlock European prejudices that Maori are not able to identify safe, healthy behaviours.

The period when participants were taking action to deal with their symptoms was submersed within the social environment of each individual. Symptom onset and delay times differed for each participant. Responses to symptoms were mediated by gender and culture in relation to what was happening in their environment. Rules guide behaviour and breaking them leads to disapproval or negative consequences. Rules are there for a good reason. Rule concepts trigger a further set of research inquiries such as why rules are developed, changed, or broken and what are the consequences of broken rules (Argyle & Henderson, 1985). One example of broken rules is where two people may be close friends and one person may betray trust by an unacceptable action such as lying to the other person instead of being truthful if the lie is discovered, the friendship may end. Rule concepts command people's response to heart symptoms. These codes are sets of cognitive rules (Argyle & Henderson, 1985) that are activated by the onset of symptoms. They are unwritten, unspoken and often unconscious scripts mediated by gender and culture and they determine the preferred coping strategy.

### **European women's difficulties in recognising heart disease symptoms**

The mixed messages women receive about symptoms associated with the ovarian cycle; menstruation and conception follow them throughout life. These biological processes are inseparable from their sense of self. Women behave according to a set

of rules handed down through generations. They are taught to hide evidence of their menstruation especially from men. Adolescent girls learn to cope silently with the cyclical rhythms and changing sensations in their bodies. Women have been traditionally perceived as at the mercy of their body rhythms which make them physically frail, irrational and emotionally confused. As young women learn about their sexuality it is accompanied by the discomfort of menstruation and contraception, body shame, as well as loss of equality with boys. This training contributes to a woman's diminished sense of self. The reality for women in today's society is that they go into womanhood coping with symptoms that are the side effects of contraception at relatively early ages. It is not surprising that women learn not to express their inner fears about pain or discomfort to doctors. Or, if they do express pain they describe it in vague terms, which mimic gynaecological ailments with the accompanying non-descript terminology (Kitzinger, 1985).

It is the vague language that encapsulates the difficulty in diagnosing heart conditions for women. Women are given permission by the nature of their socialisation with menstrual symptoms to be vaguely unwell. Women had spoken about their symptoms with more ease at the beginning of the interviews and they conveyed their feelings more openly. When women participants consulted their local doctor about symptoms such as in the case of one woman who had shortness of breath, they often describe their illness in vague, polite language. This participant went to the clinic stating that she was unwell, but did not describe her shortness of breath. Her doctor checked her blood pressure but did not conduct an ECG test to determine whether or not she had suffered a heart attack. Stereotypes permeate attitudes towards women's illnesses. Women participants described themselves as acting in a polite, not particularly assertive way when they approached their doctors. As a result they were not perceived as in much distress or pain, so they were sent home to rest. Insidious stereotypes of passive women (Naidoo & Wills, 2000; Oakley, 1976, 1981) continue to describe women who retire from the world to their bedroom to rest their delicate dispositions. This woman was being treated as a with female ailments and not diagnosed as being at risk of a heart attack, which both women and their doctors were socially conditioned to think of as a man's disease (A. Miller, 2001).

### **European men's difficulties in recognising symptoms**

This study emphasises women's symptom interpretations so the discussion of men's confusion about symptoms will be covered in the sections, confusion about heart attack messages and confusing contemporary health threats. As previously reported European men attributed their symptoms to indigestion, or a sore arm or perceived that they had no serious symptoms. They described symptoms in a low-key manner or in vague terms. They had similar difficulties to European women in recognising symptoms. Further discussion about European men's symptoms will cover the ways that they endure their symptoms in Chapter Eight.

### **Maori symptoms**

Contrary to larger studies (ARCOS) (Bullen, 1997) where Maori were found to underreport severe pain these men were able to convey their experience of severe pain in a Maori setting. One man talked about his pain in the context of being stressed out and he referred to this situation in Maori terminology. There is further discussion about the ways Maori men endure their symptoms in Chapter Eight. If a Maori person talks about heart attack symptoms they will be more likely to behave according to the tapu and noa rules within their culture. Maori people are quite reluctant to talk about symptoms because they perceive the illness as risky or unsafe.

Traditionally, for Maori, the consequences of talking about any symptoms was difficult because ill health was perceived as a transgression of tapu which might lead to more catastrophic events. The word that Maori people use for symptoms is 'tohu' which is linked to 'tohu iho' the name for burning fires that indicate where a Maori chief's boundaries lie on the tribal (iwi) land (whenua) (Walker, 1990). Historically, if strangers crossed the boundary lines, or if a tribe member metaphorically steps over the boundaries with behaviour unacceptable to the tribe (iwi) a tapu has been transgressed. Therefore, the Maori individuals need to act in ways that are acceptable to their culture. This is why they tend to down play symptoms and deliberate with whanau before seeking medical attention (M. Durie, 1994; Walker, 1990).

### **Maori women's difficulties in recognising heart disease symptoms**

Maori women were conditioned to the pain of childbirth through the ancient custom of Te Ao Tawhito. Maori Government legislation and urbanisation gradually replaced

traditional Maori childbirth practises, which led to hospitalisation of childbirth (Ellis, 1998).

Maori women participants were very reticent about their symptoms because similar to European women they have been socially conditioned to conceal their symptoms. Maori women discuss symptoms with older women. Maori women's responses to heart symptoms are bound by traditional values. Maori women's bodies are perceived to be tapu in the head, heart and genitalia. Figure 6.1 is a contemporary painting of the mythical figure of Hine-titama. It represents how Maori women have reclaimed the symbolic history and language and applied it to their present day gendered experiences.

Figure 6.1: A painting by Robyn Kahukiwa called Hine-titama, daughter of Tane and Hine-ahu-one a fusion of godly and earthly elements (Kahukiwa, 1995, p. 35)



The conferment of tapu was designed as a health safety measure. Their symptom experiences are linked to traditional practices before and after menstruation and childbirth, which is similar to European women. The difference between the two groups of women is that a tapu law of whare kohanga influences Maori women's behaviour.

When women were considered to be tapu they were separated from other whanau members at times when they were menstruating or giving birth. These customary practices were designed to reduce infection and facilitate the recovery of the mother and baby. Only kuia (senior women) were allowed to contact, advise and support the mother and child. In this context Maori women traditionally seek out kuia to discuss symptom experiences. Thus symptoms are discussed with women and then male whanau members are called for assistance such as providing transport to the doctor (M. Durie, 1994).

When Maori women were describing their symptoms they downplayed the importance of their symptoms. Three Maori women reported their symptoms in low-key terms. The interview process revealed that they were reluctant to talk about symptoms. The women were interviewed by a Kuia (senior woman), but it was hard to draw them out during the taped session because the symptoms were perceived as tapu. Considering symptoms as tapu or risky makes them difficult to talk about. Traditionally if Maori custom was broken through a breach of tapu rules Maori perceived that the consequences would be the onset of serious illness or catastrophic events. In contemporary times symptoms of illness in an individual directly impacts on the wellbeing of whanau members which is interpreted as a risky or unsafe state of affairs. Therefore, Maori are reluctant to report symptoms because any illness they have is the responsibility of the whanau group. The whanau group works together to achieve wellness for a sick member, which realigns the whanau, back into a state of wellbeing.

These descriptions demonstrate critical areas in Maori women's heart health. Minimising or under-reporting of symptoms has been demonstrated in larger studies (ARCOS) (Bullen, 1997) as a trend over time. In the past interviews in large studies would have mainly been conducted by European health professionals (M. Durie, 2001). Under reporting of symptoms and whakama (shyness) has been construed as lack of knowledge by Maori in relation to heart disease. This type of blaming Maori ignorance has masked the cultural reality of Maori women's symptom experiences and the hidden survival codes.

The next section contains the discussion relating to participants' expectations about their symptoms. The main issue arising out of participants' experiences is one of confusion from several different sources. These sources are: not expecting symptoms to be heart related, not knowing about thrombolytic therapy, doctors becoming confused, confusion about viral symptoms, confusion about heart attack messages and public perceptions of emergency services.

### ***Women's expectations***

The researcher reviewed the literature relating to the concept of expectations. In the self-regulatory model (H. Leventhal et al., 1997) expectations fit neatly into perceptions of how long the illness will last, the physical, social and economic consequences of the illness and calculations about the recovery period. But the researcher found that the point where expectations ended and coping actions came into play was blurred. The data provided an extremely complex portrayal of expectations where social roles impacted on the participants' expectations. This was a difficult task for the researcher as it did not fit neatly into symptoms expectations, lack of knowledge or expected outcomes. In the 20<sup>th</sup> century, women tend to live approximately six years longer than men, which is attributable to the decline in mortality from infectious diseases and number of births. In Britain, over 60% of general practice consultations involve women. There are many explanations for these consultations such as patriarchal control over childbearing, depression as a result of social isolation or that women acknowledge their feeling of illness. When a woman participant went to the doctor he gave her the reassurance that she expected within the bounds of her socially constructed role. An explanation of this behaviour is that women have been "socialised to be passive, dependent and sick" (Naidoo & Wills, 2000, p. 37). It was normal for her to have her blood pressure monitored and she did not expect to have a heart attack "*come back a couple of days and we will have a check of that*". This text was assigned to communication and outcomes. But as it turned out she had been having a heart attack (which she did not expect) and was misdiagnosed. The outcome (misdiagnosis) was influenced by her gendered role and expectations about her symptoms and the perceptions of her doctor. It is only by constructing new accounts of women's symptom experiences from a feminist standpoint, which explore the relationship between heart symptoms and the construction of women's identities that delays in care seeking will be resolved.

## Summary

This chapter consisted of three parts. Part One has reported the participants' delay times for seeking care for heart disease symptoms. Part Two has identified the way symptoms are described by lay people who use markedly different language to that of health professionals. However it is important that the 'original' symptom descriptions are closely examined, as they are the foundation of participant's perceptions. The participants related their own experiences of pain in ordinary sounding terms, which uncovered the hidden meanings, which showed the researcher that they were behaving according to socially acceptable rules. The theoretical base that emerged with pure symptom descriptions was explained together with an explanation of underlying factors such as women's experiences with childbirth pains. The biggest point of difference between women and men's symptom experiences was that women experience more gynaecological symptoms that are bound to influence their perceptions of care seeking. Part Three covered the findings about participants' symptom expectations. When people appraise their symptoms they consider the positive or negative consequences of their symptom experiences. The findings have shown that most participants were not expecting their symptoms to be heart related. Participants were confused about symptoms that they thought were a viral or 'flu like illness. Participants who experienced symptoms that were vague, intermittent or caused mild discomfort did not associate them with melodramatic portrayals of heart attack messages in the media. The discussion of both categories has covered symptom experiences in the initial context of coping with heart symptoms. It includes the difficulties people have recognising heart symptoms, symptom expectations, and beliefs about symptoms.

These categories set the scene in the following chapter for the many ways that people have the need to talk to people in their close social milieu and how they obtain reassurance about worrying symptoms.

## CHAPTER VII: RESULTS - MAORI DIMENSION

*I can't sleep at night, because even at night I'm worrying about things and planning things. It's the mana, you see. If you've got it, it never leaves you alone. You have to be thinking about the people and working for them, all the time. ... Dame Whina Cooper Veteran Maori elder (Te Rarawa) and Civil rights campaigner (Quotable New Zealand women, 1994)*

### Overview

The chapter is in three parts. Part One covers Maori beliefs about the heart and provides information from three key informants according to their personal views. Part Two discusses traditional health treatment. Part Three identifies influences on care seeking. This chapter establishes some background information, which has been placed into common themes. These interviews set the stage to establish the Maori perspective on the heart. The following information contained within the korero (conversations) conveys the personal perspectives of the three informants. The second part covers a discussion of the themes. The discussion section covers Maori perspectives about care seeking, Maori beliefs about the heart and the influence of poverty that affects care seeking. Then the chapter is summarised.

### Introduction

The interviews with the informants set the scene to establish the Maori perspective on the heart. The following information contained within the korero (conversations) conveys only the personal perspectives of the three informants. The informant interviews allowed the researcher to establish some background information important and relevant to the Maori analysis of the data. Maori still pass information down through the generations through oral traditions such as the formal speeches on the marae. The researcher contacted the university librarian responsible for Maori publications to find out whether there was any formal publication about Maori views of the heart. According to the specialist librarian there were no published articles about Maori views of the heart. After consulting with Maori colleagues the researcher decided to conduct the key informant interviews. The information contained within the interviews provided rich data about the heart and influences on Maori ways of

seeking medical assistance that was unattainable in a more formal sense through library databases, to researchers. The following themes emerged from the informant interviews and they acted as a base for building up the Maori data set.

### **Part One: Maori beliefs about the heart: Informant data**

This category means that, according to one informant, Maori retained traditional beliefs about the heart and included these beliefs when making decisions about modern medical treatments. The interview raised some hidden points about Maori health care that are not found in formal publications. First of all there is a difference in perceptions of health care between older and younger people. The topic of heart transplantation was used as an example:

*Older people would say they wanted no new heart. Their attitudes were based on old beliefs. But they have two attitudes if their children or grandchildren needed one they would say go ahead. So there is a difference between me and others (emphasising this point) it is the young/old divide. (Informant 1)*

Secondly, the Doctor explained through stories how tapu beliefs survive, evolve and are still used today in Maori perceptions of health care where the doctor was referring to Maori resistance to autopsy procedures following a death.

*So time has changed attitudes. Although it has changed by degrees and the concept of tapu overrides this with degrees of tapu. This can be seen in the concept of interfering with bodies. (Informant 1)*

The informant used some historical examples to illustrate Maori beliefs about the acceptability of some practices relating to bodies. According to the doctor, in the old days there were practices of interfering with bodies.

*Battle scars made with war. Enhancement of the body with tattoo. Scarification (making acceptable marks, which are left on the body. (Informant 1)*

So in the Maori way, one informant gave the researcher a lesson linking traditional beliefs to Maori reactions to modern medicine. Hearts and heads were tapu body parts in ancient times but tribal practices of tapu could change according to the circumstances. According to this general practitioner, in Maori society, today, beliefs about tapu and noa influence their attitudes when seeking health care. Older people would be consulted about the health crisis and were more likely to find a way through traditional beliefs to give permission for younger people to undergo life saving surgery like a heart transplant.

### **The symbolism of the heart for Maori women**

This category describes the views of one Maori woman. Maori women experienced symbolic beliefs about the heart related to their cultural heritage. She chose a quiet place under a tree and began her korero (talk) about the meaning of the heart for Maori women. Instead of relating feats of prowess on the battlefield she began to talk about emotions and feelings. Her description of the heart as a storehouse for feelings is similar to European descriptions of the heart as the seat of the emotions.

Robyn Kahukiwa is a Maori woman artist who has played a major part in depicting Maori women who have strong female Maori lineage. Her images link hearts and minds together with traditional tribal influences and encourage women to be a collective political force whilst identifying with their whakapapa. Kahukiwa stated that the following work is:

an expression of my Maori heart, my Maori spirit, my Maori life force  
(Kahukiwa, 1995, p. 7?)

Figure 7.1: This painting called E Hine, Ko Koe Te Whare Tangata by Maori artist Robyn Kahukiwa depicts the symbolic place of the heart.  
(Kahukiwa, 1995, p. 20)



The context is very different because the person sharing the symbolism views herself within the whanau (extended family). Her description of scars on the heart echoes the Maori doctors' stories of symbolic scarification of body parts.

*A Maori word for the heart is ngakau it means storehouse of those very deep feelings both good and bad. Bad ones are the experiences that scar you. The things that you see happen - it gets kept there in the heart. You only want to share them with selective people. You carry them - with the most beautiful taonga (treasures) in your heart. Your heart contains the most beautiful things people have told you. My immediate picture is my mokopunas (grandchildren) being born - the beauty of the birth - seeing them talk and to play with them. Some stories that people tell you write them on your heart. (Informant 3)*

Her description of the heart is linked to her womanly experiences, her role as a woman, mother and grandmother. She relates the symbolic meaning of the heart through the oral tradition of stories connected to her experience of womanhood and childbirth. So her experiences of heart sensations are directly tied to her female body functions.

*There are different categories of love Te Kianga is the practising of values to get things right - especially if you are not receiving the type of message you want to hear. The heart metaphor is the strongest authority when people are making a point. When you draw on the heart your whole being is asked to account for. (Informant 3)*

Other symbolic meanings related to the heart and body are the different interpretations of love that are particular to Maori and conveyed through the personal experiences of this Kuia.

*The heart has other values: manaakitanga is overall supporting love, te aroha refers to the heart as a symbol of love and caring tied to the heart strings, rangimarie means peace within the heart, and wairua the spiritual dimension of the heart. These are all drawn from main heart values. The principle is... If I haven't been loved then I find it hard to love. It is related to body parts where women wash and who washes after them. Houses that have no water mean that it is restricted for women to wash because that is the end of the water (Informant 3)*

She explained that wai (water) is used in spiritual and symptomatic ways for traditional healing.

*Nga tonu waa ka hua. How in its time it will come to fruition. This vision is from women before you the heart is that sense of duty to do things know its right the body moves in the rhythm to make things happen. Nurturing and caring can move mountains. It is a force within. (Informant 3)*

She described that the symbolism of the heart to Maori women is similar to that of European women. The essence of what she said is that female body functions of menstruation and childbirth are connected to their feelings and heart sensations and pain experiences.

### **Summary of beliefs about the heart**

According to these two informants, hearts were regarded as tapu just the same as other body parts such as heads. The Maori word for the heart is ngkau. Maori beliefs about the heart include values about love and caring such as manaakitanga, te aroha and rangimarie. Similar to European beliefs Maori perceive that the heart has a spiritual dimension that is called the wairua.

### **Part Two: Traditional health treatments**

This category means that according to one informant, Maori customary ways of treating illness and healing are explained. Although there are written records of Maori traditional medicine - formal oral instruction in medical practices is given at the discretion of the Kaumatua. The following instruction is a powerful and important gift to the researcher given to increase understanding about Maori lives through the sharing of knowledge. These are his personal stories and opinions.

*Historically, The Maori tohunga never cut the body to heal the heart. So it is important to share what traditional knowledge I have to support modern heart medical practices. (Informant 2)*

He went on to explain about traditional Maori lifestyles.

*Each riverbed they were catching eels and smoking them out there. When you're sick the tohunga is called. He will come and you been sick a member of the family been sick (Taha Whanau. No one seemed to know how it came about. No worries (Taha Hinengaro) you get this pain nothing else just the pain and you know the tohunga will summon the whole marae. He will question the children ... everyone there are others (Taha Whanau). Quite a few came forward they would sit in a ring and would give them raw honey from a cone He broke off a piece of a cone each he told them to eat the honey He gets his orderly to get some cold water, cold water and honey.(Taha Wairua and Taha Tinana - the food and water has a spiritual and physical dimension). A certain element the tohunga seemed to know the problem and*

*his cure was the honey and water, then, they chew the honey and spit the wax out (Informant 2)*

This Kaumatua had explained his experience of traditional ways of healing and medical instruction that took place during his lifetime.

### **Traditional treatment for chest pain**

This category means that one informant, (the oldest Kaumatua) described how Maori were treated for chest pain according to their healing methods and customs. This Kaumatua presented his personal experience about how Maori treated chest pain. The pattern of care seeking is arranged elegantly for the ears of the listener. First there are symptom descriptions couched in physical, mental and spiritual terms. Then the medication is prepared through washing in water and administered after the protocol of a karakia.

*I was about 7 or 8 and we used to travel on horses to tangis we used to travel from where we lived near Whakatane near Ururewas to Rua's stronghold Maungapohatu (whenua and whakapapa). We travel right back there and on our way through there were eighty of us on horse back eighty grownups and kids my sister and I were able to ride so we had our own pony we were double-back on our pony my sister and halfway through the forest we was going up to Maungapohatu the tohungas in the lead he put a hand up everybody stop and everybody gets off their horse and everybody ordered to go on the side and sit down, the chief wanted to make a speech the chief called out and said we have people here who are very ill they couldn't travel on the horses any longer their chests are hurting (physical description) so we have to stop here (recognition of symptom's importance) the pains are right in the chest (diagnosis through the location and intensity of the pain) things aren't right in the chest (mental and spiritual links to the painful symptoms) the shape of the horse it was hurting them so. He ordered all those about eight very ill he come and had a karakia (spiritual protocol) then he said to his orderlies go up to the slips in the forest for wild puhas which they did bring back bunches of puha so they brought back bunches of puha and they took it down to the creek and they washed it they washed it clean. Puha is very*

*bitter you know (rapid preparation of medicine). Ohhh its terrible you know. So here they were handed out these puha and they were told to eat it, eat the lot eat it raw..and they did sit, where they were, the pain was gone (fast access to treatment) the tohunga said to us in future you get that pain in your chest area get the puha get the puha fast and then eat the whole lot of it. (Health education for acute events in a tribal context) (Informant 2)*

The Kaumatua described how Maori had ritual and treatments for chest pain. His personal story is a strong contrast to the following discussion about Maori symptom responses in modern healthcare settings.

### **Modern Maori responses to bodily symptoms and chest pain**

This category contains the views of one informant, a general practitioner who had experience with Maori presenting at the medical clinic for symptoms of illness and chest pain.

*Human nature is what it is. Maori basically downplay symptoms. Maori sit on symptoms, contemplate symptoms, try and decide who to talk to Aunty, Minister Tohunga. My clinical experience tells me that they delay reporting all symptoms. This particularly is so for Maori men. (Informant 1)*

He explained that several things would be going through their minds when experiencing painful symptoms.

*Men and women will first think shame whakama that they are sick. They will feel guilty because they are still smoking. They will have no money to pay they will have no clothes they will have holey underpants these things are doubly so for women. But women delay longer. Women are traditionally stoic. They immediately respond to the needs of those around them. (Informant 1)*

The Maori doctor recalled his clinical experiences of Maori responses to chest pain. The importance of discussing symptoms with family was part of his clinical experience.

### **Summary of chest pain**

According to one informant, Maori had traditional rituals and treatment for chest pain. Another informant explained that Maori would be worrying about the shame of visiting a doctor either because they continued to smoke cigarettes against medical advice or that their poverty would be embarrassingly obvious if the doctor caught sight of their ragged underwear.

### **Part Three: Influences on care seeking**

There are distinct influences on Maori care seeking behaviour that are different from that of Europeans. According to two informants, the following themes influence Maori perceptions as to whether or not they will seek prompt medical care.

#### **Maori women seeking contemporary health care**

This category describes the specific challenges that arise for Maori women when seeking health care and that they occur in many ways. Maori women are whakama (shy); it is part of their identity so they are reluctant to attend non-Maori health services.

*Some women are very slow, you almost have to pick them up and take them...denial ...They think. It'll get all right tomorrow. A little rub... a little to drink...they will always put it off especially if they have to go to a meeting... those that get so much out of their people. Taihoa. (stop) they know it is something. Get a bit frightened. If it is to do with the heart they get a bit superstitious. I think so.... Probably they turn it into something else... .my asthma.. getting old.. playing it down... until it puts them in stop. They go with someone else for a check up someone they trust... they will go to someone that they trust. When diagnosed they almost seem surprised...Afterwards..they have to have people around not medical but to talk always have to have people around..(Informant 3)*

These comments encapsulate the Kuia's personal experiences of Maori women's care seeking attitudes, where they endure pain, get worried about it or have superstitious beliefs, and put family needs ahead of their own, then carry on with social obligations

### **Poverty influences care seeking**

The meaning of this category, according to two informants is that Maori people are unable to visit a doctor because they cannot afford to pay medical fees. All informants directly addressed poverty as the most significant obstacle to obtaining medical assistance.

*Visiting the Doctor in correct clothing was an embarrassing concern for women. At times they have to rely on family members and borrow clothing maybe. Someone will come in and dress them up. Make sure that they have got things. When they decided to go they get the underwear and brush some of that up. For an older person they may be out of the bra range so just come in a singlet...(Informant 3)*

Poverty caused significant embarrassment when Maori attempted to seek medical care. The costs of medical fees, the lack of money for public transport, not having enough decent clothing and the money lost through time away from the workplace were all sources of shame for Maori.

### **Whanau influences care seeking**

This category means that according to two informants, whanau (extended family) ties, obligations, connections and support are extremely important for Maori at times of sickness. Uppermost in Maori women's minds is to attend to their family responsibilities such as arranging care for children or grandchildren. So the clinic visit is delayed until childcare is organised. Having family support at the medical clinic is an integral part of Maori culture. It can contribute to delays when the sick person waits for other family members to accompany them. On the other hand whanau responsibilities or occasions can be used as an excuse to put off clinic visits or hospital appointments.

*They think whos going to look after people once I go to hospital I got to get them arranged before I go. They are nervous about the procedure what is going on. They want to know what is going to happen...If they are older who is going to accompany them the person is made to promise that they are not*

*going to leave them. But the medical clinic is not happy...They fear being left alone. They also might have functions that they want to be present at church birthday.. So they don't want to go to hospital Whanau makes them come they'll say I just got better. (Informant 3)*

*When they come they have accepted that there is something wrong with them. Women will talk more easily than men (Informant 1)*

Whanau support is central to Maori health and wellbeing, events within the whanau context can serve to aid or impede care seeking.

### **Doctors' communication influences Maori care seeking**

This category describes the views of two informants, which were that Maori felt more relaxed about visiting the doctor if they were made welcome, didn't feel rushed and some of the discussion was couched in Maori language. This Maori clinician explained the steps that were necessary to conduct an effective diagnostic interview for Maori patients. Establishing trust and acknowledging their Maori ancestry is an integral part of the clinical protocol. Allowing more time for the clinical interview was considered vital. Maori reluctance to discuss bodily symptoms was dealt with in the following ways.

*It is most important to get a feeling that the doctor is listening. They need to tell everything, which might help the doctor they like to have time to have a korero (Informant 3)*

*The doctor will work really hard digging really hard to elicit symptoms. Suggest things Listen carefully pick up on them Throw questions to see if the answers are consistent Rely on the information given by them to determine what is going. It is bad practice to accept things at face value. (Informant 1)*

*Use the korero their language that's good. I want to hear that the doctor has to be like a camera to get the focus on what they want. There is nothing better for Maori when they are interviewed than to hear back bits of their own Korero back. You are buying them in (Informant 3)*

*They usually know about someone who went to the doctor didn't come back that's a real fear...(Informant 3)*

Using Te Reo Maori (Maori language) to welcome people and describe their illness is an important part of obtaining an accurate diagnosis. Longer interviews were perceived as a more efficient way to run the medical practice, as the real source of the medical problem would emerge. Maori are a population with personal experience of high mortality rates. Establishing trust within the doctor-patient relationship was given high priority from these informants. A closer focus on the medical interview process was considered essential for dealing with Maori who are markedly reluctant to discuss symptoms.

### **Summary of care seeking**

The barriers that inhibit Maori from accessing appropriate medical care are whanau responsibilities, a lack of money to pay the doctor's fee and Maori feel embarrassed about consulting a doctor because they are reluctant to discuss symptoms. Also, Maori would be concerned about not possessing adequate, or respectable clothing to attend the medical interview. For Maori to be motivated to attend medical clinics on a regular basis they would need to have a good relationship with the doctor. Maori perceptions about the communication style of their local doctor made would influence their care seeking behaviour.

### **Summary of informant data**

The informants related their views about Maori symbolism and beliefs about the heart. They covered some important aspects of traditional Maori health models and treatments, as well as more modern concepts about the impact of medical treatments such as heart transplantation procedures. The influence of poverty on Maori access to medical care was explained and linked to Maori embarrassment about consulting a medical doctor. Doctors' communication skills for Maori were perceived as very important in conducting an effective medical consultation.

## Discussion

This discussion will focus on three important elements related to care seeking for Maori. First, Maori perspectives on care seeking will be discussed, then Maori beliefs about the heart will be explained and finally the influence of poverty on care seeking behaviour is outlined.

### Maori perspectives on care seeking

The Kaumatuas' stories provide some insight in Maori health practices and care seeking. Although they can be related to Maori health models in the literature they are only stories from one person's perspective that cannot be verified. What is the point of using these stories to address the modern problem of 'patient delay' for AMI symptoms? Oral tradition in Maori society continues to shape not only beliefs but they also impact on the way knowledge is passed from one Maori to another. The orator's skill is prized, their knowledge of the whakapapa (ancestral lines) (Walker, 1990) the use of metaphor, and the subtle way they weave vital information for tribal survival through stories.

What has the Kaumatua's care seeking episode set approximately 75 years ago got to do with obtaining clot-busting medicine in contemporary society? This story provides the clues to Maori care-seeking for chest pain. It establishes the socio-cultural context through the whenua (land) and the whakapapa (tribal lineage) where the bodily sensations of chest pain occurred, the responsibility of the rangitira (chief) for his iwi (tribe) is shown through his authority. He stopped and tended to the eight sick people. His voice is heard describing the symptoms and consulting with the rest of the tribe. A karakia was performed before the orderlies went to gather the medicine called 'puha' (sow thistle). Prompt medical treatment was undertaken in the form of eating washed raw puha. The chief gave his tribe an edict if they had chest pain to get puha immediately then eat it all at once. The content of interviews from Maori participants provided vital clues when analysing the field data as many of the participants showed how difficult it was to discuss symptoms and issues related to the tinana (body), wairua (feelings, spirituality), whanau (extended family) and te hinengaro states of mind (M. Durie, 2001). Medical scientists have tested Maori medicinal compounds or rongoa. Manuka (a tea tree) honey is now regarded as a natural antibiotic (Ahmed,

Hoekstram, Hagem, & Karim, 2003). In contemporary medicine, it is used quite widely for healing skin infections or burns that do not respond to the usual range of antibiotics.

### **Maori beliefs about the heart**

The Maori way of describing the heart is quite different to European thinking. The Kuia described it as a storehouse. This was her personal point of view. Storehouses (pataka) were built for food to provide continuous disease free nutrition for whanau members. Tapu rules applied to storehouses to ensure fair food distribution. Therefore, hearts were surrounded with tapu beliefs (M. Durie, 1994). When discussing Maori values about the heart the Kuia drew upon Marae-based values, which guide heart symbolism. Maraes (meeting grounds) are pieces of ground in front of meeting houses in towns or cities. They have increased in importance after Maori urbanisation as political forums for communication and social obligations. Durie (2001) notes that there has not been sufficient appreciation of marae encounters that shape behaviours and “codes of living” (Walker, 1990).

The Maori woman’s description of feelings about the heart was couched in terms of marae protocol. The marae encounter reflects how values shape behaviour. Durie (2001) states that a speaker’s words are viewed as an oath as binding as statements in Law Courts. Behaving in the right way through oral tradition on maraes by receiving public challenges or being accountable to whanau is connected to symbolic love emanating from the heart. Maori psychological values emphasise collective responsibility; the Marae is a forum for airing these concerns. The meanings are set down in terms of regulated behaviour through tapu beliefs about personal boundaries between women and men (M. Durie, 1994, 2001; Ellis, 1998). For example, water used for washing the body removes physical and spiritual contamination. When women wash a newborn baby it is referred to as a tohi ritual where a new baby is immersed in water (M. Durie, 1994). Maori women differ from European women because they interpret these experiences through the Maori psychological and physical domains of tapu and noa (M. Durie, 1994, 2001; Ellis, 1998).

### **Poverty affects Maori care seeking**

Primarily, it is social and economic factors (M. Durie, 1994; Ellis, 1998) that impinge on Maori women accessing health services such as a lack of adequate Maori housing, high rates of unemployment and lower levels of education. Maori are more likely to have co-morbidities such as asthma, hypertension or diabetes. The symptoms emanating from other illnesses such as asthma (where the symptoms are tightness in the chest area and shortness of breath) can be confusing as to what is the exact cause of the health problem. Lack of trust in non-Maori health services is an important factor that impacts on access to health care. Trusting the health provider and whanau (extended family) support is crucial for Maori during the entire care seeking process. He korowai oranga the health and disability policy states that all people in New Zealand with lower incomes have lower health status. Maori are reported to have poorer health than non-Maori regardless of education or income level (New Zealand Ministry of Health, 2002). Durie (1994) perceives conventional measurements of Maori health (death rates, life expectancy or socio-economic status) as statements about the differences between Maori and non-Maori. While these differences are significant they are portrayed as the personal failure of Maori rather than addressing the failure of a monocultural health system. Whakama or shame at being Maori and reluctance to confide in the doctor because of perceived ethnic stigmatisation.

When the issue about care seeking came up in these interviews poverty was mentioned first and seen as a significant problem. On fieldwork visits the mobile Maori nurses attached to the Health Trusts explained that they had to address the issues of poverty and lack of transport when treating clinic patients with chronic illness such as diabetes, congestive heart failure. Money for transport and having the correct clothing were scarce resources for many Maori needing medical care.

### **Summary**

The discussion of findings from the three Maori informants shows that there are three important aspects that affect Maori when they are making decisions to seek medical assistance. Maori identity is a strong influence on Maori attitudes to seeking care from the medical profession. If Maori feel comfortable with, and accepted by their medical practitioner they will tend to keep clinic appointments and return for check

ups. A significant concern for Maori is poverty through having a lack of money to pay the doctor's fee or not having enough respectable underwear to wear for the physical examination. This chapter has provided background information about Maori health beliefs and care seeking from three senior Maori key informants (two Kaumatua and one Kuia). They shared their personal experiences and knowledge. These Maori perspectives were compared and common themes were developed from the information. The three main themes were: Maori beliefs about the heart, traditional health treatments and influences on care seeking. The information from this chapter will help to inform the discussion from the literature review related to Maori participants' findings.

## CHAPTER VIII: RESULTS - ENDURING SYMPTOMS

*You can see from their faces. Life was not funny. There is nothing to equal pioneering labour. For wrenching a woman out of shape.*

Ruth Dallas, The poet on pioneer women (*Quotable New Zealand women*, 1994)

### Overview

This chapter has two main parts. It provides information about how people endure symptoms for lengthy period of time before seeking help. Part One elaborates on symptoms and demonstrates that people endure their symptoms differently and only seek help or reassurance when the pain broke through their efforts to conceal it or relieve it. Part Two covers the discussion of how women cope with painful symptoms as well as how the influence of caring about others serves to lengthen the time people wait before seeking assistance.

### Introduction

Primeval survival strategies lie within each human being. As the participants have shown they have survived long enough to tell the tale of their close brush with death. Part of our ancient repertoire includes the ability to bear pain over long periods. For women and men this ability was drawn from their differences, physical or psychological. Although the previous chapter has shown confusion about the origin or nature of symptoms, these experiences need to be placed within participants' immediate surroundings. Within participants' social environment there are personal concerns about people and behaviours that tie them to support systems.

### Part One: Symptoms

This chapter begins with the findings for the category 'enduring painful symptoms' this means that people put up with the pain for lengthy periods or used self-treatment strategies to relieve pain. The term endure means to:

undergo or tolerate pain (Fowler & Fowler, 1962, p. 318).

People endured pain according to their personal experiences of pain or familiar methods for coping with painful symptoms.

***Participant data - Women endure symptoms using coping strategies for childbirth***

This category label refers to women participants who automatically slipped into age-old coping strategies related to their womanly experiences of giving birth. Women described how they endured their symptom experiences over lengthy periods of time. Prior to conducting the interviews with European women the researcher found women would often joke about men's lack of pain tolerance. Women pride themselves on their ability to tolerate pain related to menstruation and childbirth, which are natural biological and physical processes. It is only when the pain breaks through the participants' well rehearsed traditional strategies that other help is sought. These two women show that they used their own personal knowledge to deal with the pain. They put up with symptoms and pain until they could not stand it any longer.

*In a way I think that I have a high pain threshold because I had my five children with total natural childbirth. And I thought it would go in a while it will go in a while and I will just keep what I am doing..... that's when I got the first angina the heart chest pains. (European woman, 76 years - Retired)*

This Maori woman's pain experiences are rooted in her history of knowledge about childbirth. Her description of pain, *when the pain started to push* is similar to the way a woman's body feels during childbirth. She had just showered, dressed herself and then held herself around the chest waiting for the pain to pass that is similar to experiencing a contraction of the uterus in childbirth.

*That's when the pain started to push and it was sharp and stabbing. ...it could have been worse, much worse than what I felt. No. Oh, except giving birth. (Laughter). (Maori woman, 66 years – Retired)*

Two women described their pain in terms of their own knowledge about childbirth. It was important to them that they endured this pain, *when the pain started to push*, as long as they could in the hope it would pass, *I have a high pain threshold because I*

*had my five children with total natural childbirth. And I thought it would go in a while, like childbirth contractions.*

***Women endure symptoms without inconveniencing others***

This category means that women did not want to inconvenience their daughters or friends while they were experiencing symptoms. Women's social roles are bound up in maintaining connections with their daughters or close women friends. Women reinforce their place in society by carrying out tasks important to the welfare of others. These women remembered how they just carried on regardless of symptoms to fulfil tasks that they perceived were important. Their main concern was not being a nuisance to their daughters or friends by asking for help. This woman who was living with her daughter finally collapsed with a heart attack and her daughter rang the ambulance that arrived promptly (within ten minutes).

*I kept saying that I've got to nod off for a spell. That's when I realised it was more than just the job I was doing. ...Monday morning when I got up I collapsed, I couldn't stand up. The burning was so intense it was all I could do to put up with it. (European woman, 75 years- Retired)*

While entertaining her friend this woman felt exhausted but she kept her fatigue to herself. After lunch she experienced severe symptoms, which resulted in her contacting the ambulance staff, but endured her symptoms until care for her sick daughter was arranged. She arrived at hospital with her first heart attack in the early evening (about six hours later).

*Well I had a friend for lunch and I was feeling very, very tired. I was so tired I could hardly finish my hostessing you know. She went home about 2.00 o'clock. (European woman, 78 years – Retired)*

This woman put off ringing her daughter for approximately three hours. Coincidentally, her daughter rang her. Her mother informed her that she was feeling unwell; she tried to ring the doctor. When the daughter couldn't get a response from the doctor's phone (the message service was connected) she rang the ambulance and her mother was admitted for a first heart attack.

*I thought that's odd, they'll go away with sitting down, perhaps indigestion. They hadn't gone by 2.00 o'clock and I thought I'll have a glass of water, nothing happened, it was a Sunday. I thought my daughter it's her day in the garden, I don't want to rob her of her day in the garden I won't ring.*  
(European woman, 79 years – Retired)

Codes of endurance operate when women perceive that their symptoms may inconvenience daughters or friends. *I kept saying that I've got to nod off for a spell or I was so tired I could hardly finish my hostessing, and I don't want to rob her of her day in the garden.* They put off discussing their symptoms with family members, or use self-treatment remedies to contain the symptoms and they only take action when the symptom is causing intense pain.

#### ***Women endure symptoms while supporting their spouse***

This category describes women who put their spouse's health before their own health. It is common to find that women are actively supporting family members through serious illness. They continue to endure their symptoms without drawing any attention to them as they are socialised into nurturing roles and put their own health needs last.

*Well after my husband died I hadn't really seen the doctor at all for myself because I had been looking after him and I just carried on you know regardless and I came here one day to ask him to sign a paper for me and he said he would take my blood pressure. He found that I had extremely high blood pressure. I wasn't feeling very well at all ...* (European woman, 71 years - Retired)

This woman had cared for her sick spouse and virtually had ignored her symptoms. She put them down to flu or being below par. The doctor examined her after her husband died and found that she had high blood pressure and she had heart disease, *I wasn't feeling very well at all*, which eventually manifested itself as angina. When she finally had a severe attack of angina she had been visiting a rest home doing voluntary care (an extension of her care giving role) for older people.

### ***Women's self esteem is affected by enduring painful symptoms and guilt***

This category label refers to women who felt more physical pain and psychological distress when they underwent cardiac surgery and were more distressed about lifestyle changes. The final interview question produced an important angle that the researcher did not expect. The question was: Is there anything else you would like to tell me about your heart disease? It revealed that the impact of cardiac interventions and instructions from doctors about risk factors was different for women than men. Women's identities and self-esteem are linked to their perceptions about the public acceptability of body image. These perceptions then have an impact on women's self esteem. Self-esteem is defined as:

A person's own individuality or essence

Think favourably of, regard as valuable (Fowler & Fowler, 1962, p. 330)

*I have a scar from here down to here one inside (points to the sternal area between the breasts) my neck and down my leg, from my knee. Through to the groin (European woman, 76 years – Retired)*

*You know this wouldn't heal up it was like a big lump of meat. It kept breaking out, I had bits of sticking plaster over it and what have you. I think the worse pain was up here (points to the top of her right breast) I make sure I haven't got anything too low so that it doesn't show (European woman, 73 years – Retired)*

After a diagnosis of an acute myocardial infarction and, or, subsequent surgery there are additional pressures on women's self esteem about body image by referring to the scars in ugly terms, this wouldn't heal up, it was like a big lump of meat.

### ***Maori women endure symptoms because of whanau responsibilities***

This category means that Maori women endure pain because they have enormous whanau responsibilities. Maori women endure their symptoms while carrying out their daily responsibilities similar to European women. The difference with Maori women was that seeking help for heart symptoms was influenced by the role of Maori

women within their whanau. Maori women have responsibilities for their immediate family. Also they have significant roles and responsibilities within their tribal group, which extend from family members, to hapu (subtribes) and the larger iwi (tribal groups). One woman was forced to make an appointment with her doctor when she could not endure her symptoms any longer.

*I was still working but the symptoms I got was mostly, ah, I was puffed out*  
(Maori woman, 68 years – Retired)

*Ah, yeah. That's what made me go to the doctors, is that, you know, you got sore, heavy, (indistinct) and then it's painful too, you know.... But when I rub it, I, it seems to help, you know... You know I was on the move all the time down there. Opening places, huis and tangis, on the go all the time down there. .... Mostly something to do with the families you know, kids and that*  
(Maori woman, 72 years – Retired)

They were more concerned about the disruption to whanau members' lives, *opening places, huis and tangis, on the go all the time*, in the context of extended family than their own health. The way that they lapsed into indistinct replies during the interview shows that they were embarrassed and were minimising their symptoms *you got sore, heavy, (indistinct)*, according to tapu (not safe) that was a signal of a health threat. Also they were reluctant to rely on whanau (extended family) for help *family's all working, you know*, because that requires a change in their role within the extended family. Another important consideration was the expense of visiting a doctor *only \$2 or whatever*.

*Family's all working, you know, ... the only thing I pay is my medicine. Oh, and that's not much, only \$2 or whatever.* (Maori woman, 72 years - Retired)

The following quotes illustrate how Maori women endure painful symptoms, *you got sore, heavy*, over time until they are forced to seek medical attention. It is these burdens rooted in contemporary Maori society, *opening places, huis and tangis, on the go all the time*, and economic deprivation, *not much, only \$2 or whatever*, that stops women from visiting medical clinics until their health is seriously affected.

### ***Men endure symptoms while considering others***

This category label means that these men are using codes of honour befitting men who were considering others, but knew that their spouses and daughters would assist them. They were concerned about maintaining their responsibility and dignity. These men described how they coped with their symptoms. Previously, he had been diagnosed with angina and had an angioplasty procedure to open his blocked arteries. He had experienced a lengthy period without heart symptoms. His account of this acute episode shows that he was concerned and cared about his wife and tried to continue walking while experiencing considerable pain. He finally had to sit on some steps because he could not reach the car. His spouse drove him to hospital where he was admitted to hospital with a first heart attack. This man's acute event occurred within five minutes drive to the nearest hospital emergency department and an ambulance would not have been able to get him there any sooner.

*I said to her I don't think things are right because the same pain is coming on except that it is worse. ... She said right stay where you are and I continued to walk down the road. (European man, 64 years - Chief Executive)*

This man described bearing his pain until he could get inside and go to bed. Then he went for a shower.

*And I gradually made it inside and lay down for a while, about half an hour and things sort of settled down and didn't come back. I went and had a shower. (European man, 62 years – Technician)*

He continued his mowing after his symptoms settled, then got settled on a chair and waited for his wife and daughter to come home. He referred to his symptoms as if they were not bothering him too much: *I was just uncomfortable*. He never considered disturbing their morning worship at church to attend to his discomfort. When his daughter arrived home she rang for an ambulance. This man was admitted to hospital for his first heart attack and subsequently underwent heart surgery in a private hospital.

*I was mowing my lawn I was doing some raking and I felt this chest thing. I thought I had better sit down. ... I went inside and sat in my Lazy Boy but it didn't matter how I laid the thing just wouldn't go.... and waited because my wife and daughter had gone to church. (European man, 62 years – Technician)*

They had expected to get help from their family and they received prompt help in hospital: *I said to her I don't think things are right or and waited because my wife and daughter had gone to church.* These men had pursued careers that had left them in a good financial position. Both men's heart disease was recognised by doctors and they received prompt medical attention. One man had private insurance that he used to have timely cardiac surgery instead of being placed on a long waiting list for surgery that would have meant that he would suffer further symptoms and have a deteriorating heart condition.

#### ***Maori men endure their symptoms as part of their mana***

This category refers to Maori men who described bearing painful symptoms in a way that incorporated their leadership role or mana within the whanau. Mana can have several meanings, it is used to denote leadership or authority, or it can refer to personal power. Mana is invested in a person not usually because of a person's deeds but as an investment of the collective wellbeing of the whanau, hapu or iwi. These two men were not only reluctant to talk about their symptoms they were also displaying the intention to continue activities that benefited whanau. The first man minimised his symptoms and pursued a discussion about his work mate who had kept working with heart pains. He was anxious about discussing his symptoms and explained how he continued his gardening to keep up his physical strength. As it turned out he was very worried about his chest pain and diabetes because he did not want to go on a dialysis machine, which, to him, signified death.

*I remember when I was at work this particular chap, and he used to hold up. They were pains alright but it didn't prevent you doing what you carrying on what you were doing Oh the last time I had it (tape being turned on and off) and then it came on, but it (tape being turned on and off?) I was digging in the garden, something to keep the body active, (tape being turned on and*

*off)... I wake up in the morning, sometimes I'm asked, people say to me, What you doing tomorrow (indistinct) wait till tomorrow comes (indistinct) Oh yeah, it's just that I had about six relatives (tape being turned on and off?) they didn't last very long after that. Dialysis. (Maori man, 68 years – Retired)*

This man took the leadership role when he felt ill. He had been away selling mussels and made the decision to return home in spite of his wife's disapproval.

*I just said I didn't feel too well, so on um Saturday afternoon. And that Saturday we had a bit of a market day in ...(country town) and then after that then I said, oh, we go home. Sold four bags of mussels. We decided we'd come home. We came home. (Maori man, 54 years – Labourer)*

In the first man's case he viewed his physical ability as a sign of strength or mana and part of his identity to keep his body active, *something to do to keep the body active* and fit, in the face of painful symptoms for the wellbeing of whanau. During the interview he showed that he was uncomfortable even in a supportive environment to discuss his symptoms. This is demonstrated by the number of times that the requested that he tape be turned off. It was turned back on when he felt comfortable with continuing the interview. In the second man's case he felt that he could return home after selling the mussels, *sold four bags of mussels*, for the economic benefit of the whanau that retained his sense of mana.

## **Summary**

Symptom descriptions are important clues about women's socialised responses to illness. European women described enduring painful symptoms until they could not put up with them any more. Women used coping strategies used in childbirth like resting or waiting for the pain to subside. Women preferred not to inconvenience other people, so they chose not to disclose that they were enduring painful symptoms. Maori women placed the needs of whanau before their own ill health so did not seek care for symptoms until they were forced to. European men showed consideration to their spouses and one daughter when experiencing symptoms that kept persisting. They waited for the women to provide advice or assistance and take some action to get help. Maori men endured their symptoms according mana or the cultural

expectations that they would attend to the wellbeing of the whanau before getting medical help. European women responded to family members needs and illnesses before their own health needs and suffered low self-esteem and guilt as the result of symptoms from cardiac interventions or lifestyle advice.

## **Part Two: Discussion of enduring symptoms**

This part covers the discussion of how people endure symptoms without confiding in others in their social network. The way women cope with their symptoms is discussed in relation to their female experiences with painful symptoms of menstruation and childbirth. The discussion covers two important aspects of symptom experiences, which are ‘coping in wise women’s ways’ and ‘caring for others’.

### **Coping in wise women’s ways**

#### *European women*

Women are used to enormous changes in their bodily sensations that are directly linked to their sense of self. The physical expression of symptoms through each transition of their biological cycle throughout women’s lives manifests itself as changing sensations as they go through the cyclical stages of puberty, menstruation, childbirth and menopause. Therefore women learn to cope with intermittent symptoms, discomfort and pain while they are fulfilling the unspoken code of endurance whilst continuing the multitude of tasks within their role responsibilities as mothers, workers, and family caregivers.

Throughout history and in most cultures in the world women’s reproductive lives have been controlled by women. The management and structures related to childbirth contraception and abortion have been restricted to women. The knowledge base of “anatomy, physiology, pharmacology and delivery techniques” (Oakley, 1976, p. 19) has been vested in women. The control and knowledge about women’s pain and symptoms is “usually informal, often invisible and concealed” (Oakley, 1976, p. 19). It operates through a system of “cooperative mutual aid” (Oakley, 1976, p. 19) and is handed down to women over generations. Women’s worldview is that women are the ‘experts’; men are not usually involved and are only marginal to the process. There has been a reversal of the transition of male controlled medicine surrounding

pregnancy and childbirth. The renaissance and development of new midwifery services has given women the right to choose a midwife as a lead maternity carer (Shroff, 1997). Contemporary developments in women's health have provided women with women-centred choices for health services.

Modern women's lives and perception of their bodies differ from men. They have to remain more vigilant and in control of body sensations. These sensations are in a constant state of flux that emanates from their gynaecological functions. In order to sustain childbearing, nurturing family and remain in the workplace, women must be aware of their symptoms and find ways to control them as they go about daily duties. For the majority of women in this study the bodily sensations of heart symptoms were connected to their personal and biological history of menstruation and childbirth symptoms. Women's strategies for coping with heart symptoms showed that resting in between tasks and battling with fatigue were the same 'rule of thumb' used to relieve painful gynaecological symptoms (Kitzinger, 1985).

Leventhal and associates (1989) conducted two studies (Study One n=48, Study Two n=29) about active coping for childbirth. They reported that women who had attended childbirth classes presented at hospital with less pain, fear, tiredness and more energy. These studies are not statistically significant so the results cannot be generalised to other populations but they show that women use education strategies to actively cope with symptoms. As a result of women's demanding and multiple roles they are socialised to be highly aware of the body area from breasts to vulvas. Women learn to endure pain and discomfort for longer periods than men as they can often feel under par from gynaecological problems (Oakley, 1976).

The sensations of childbirth are gripping pains that spread out from deep in the pelvis and right around the small of the back. These tightening sensations are regular rhythmic and have a definite pattern. A woman watches for this pain concentrates on it and rides through it (Kitzinger, 1985; Elaine A. Leventhal et al., 1989). Angina or heart attack sensations with tightening pressure on the breast area are not that markedly different to childbirth except for the location of the pain. It is not surprising then that women respond to heart symptoms in terms of familiar womanly processes. It is easy to take the next step and postulate that women are reluctant to discuss

painful symptoms with male medical practitioners when they have been socialised to treat themselves or seek help from women's health services.

### ***Maori women***

Prior to the colonisation of New Zealand, Maori women practiced traditional childbirth according to their customary rules of tapu and noa. These practices incorporated both Maori health dimensions of health and tapu laws. Childbirth was considered a woman's domain (whare tangata) and the woman was regarded as the house for the child, by sheltering and nurturing the unborn child. Women enduring the pain of childbirth (whakmaemae) were tapu to whanau, hapu and iwi (Ellis, 1998). Contemporary models of Maori maternity care favour a social rather than a medical model. Women make choices that acknowledge their Maori identity such as whanau support at the birth or choosing a Maori midwife (Ellis, 1998). Maori women who were enduring painful symptoms would be more likely to consult an older Maori woman than to discuss symptoms with a doctor (Ellis, 1998). One Maori woman sought the assistance of her spouse when the symptoms overwhelmed her and she doubled over in pain.

Few investigators have examined the contextual factors surrounding angina episodes or an AMI. Alonzo (1986) describes this behaviour as the "acute illness episode" where various combinations of symptoms contrast to symptoms that may be experienced in the prodromal or warning phase. For these women, the question was not that they were experiencing symptoms that caused a health deviation but that whether the symptoms required more resources than were available in their immediate surroundings. It is not surprising that they put up with pain for lengthy periods and consult other people and relatives before seeking care that contributes to lengthy delays.

### ***Women's guilt about scars***

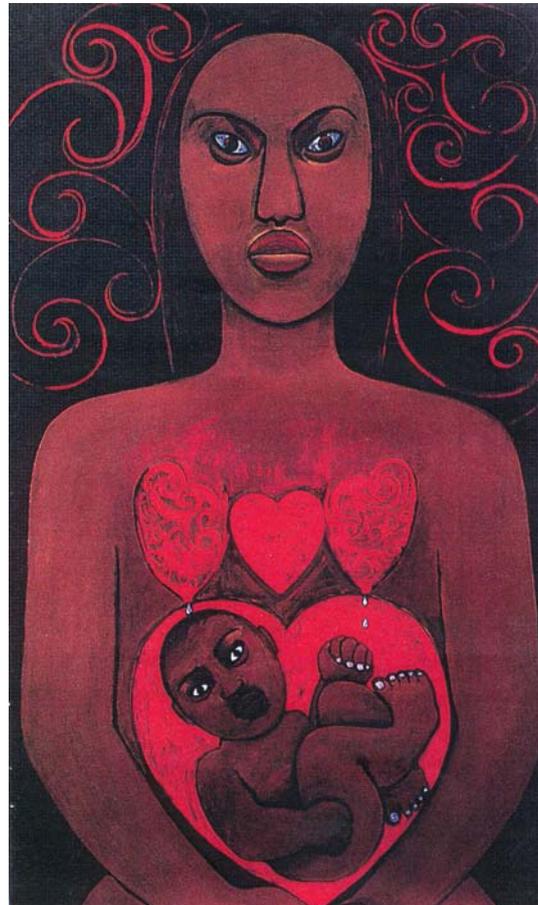
Popular culture tells women that their bodies are not good enough, that they are not the right weight, their breasts are too small or large and that their figures need attention. Women are "required constantly to shape, trim, adorn and disguise themselves to present their bodies as worthy of approval. For girls this starts in earnest in adolescence and continues for many women right through their lives into

old age. Women are taught that we dare not show our real selves and we become expert in packaging” (Kitzinger, 1985, p. 184). The researcher was surprised when some women participants raised this issue. It seems to be common sense knowledge. But because heart surgery is stereotyped as a man’s domain, the effect of mutilation and scarring around the breast area is not discussed in the cardiac literature.

In contrast men’s experiences with cardiac surgery, the scars are used as a mark of bravery and survival. Cardiac support clubs are often called ‘Zipper clubs’ to symbolise a sense of belonging for cardiac patients who are recovering from major surgery. The zipper symbolises that men have endured the pain of heart surgery similar to a ‘tour of duty’ in the military forces, the scar projects a symbol of courage and bravery (Ramm, Robinson, & Sharpe, 2001).

Women’s bodies are portrayed in the media as images of attraction to men. The images are always tweaked and glossed to provide a perfect body without scars. For women, the scars of heart surgery are a source of guilt. Their breast area has been mutilated and these scars are not so acceptable to them, as they mar a woman’s physical appearance, and impede their physical functions. The importance of the breast area in relation to the heart has been graphically portrayed in Figure 8.1. This painting shows the symbolic and physical linkages between the breasts and the heart. So the damage caused by heart surgery has profound implications for women’s bodies as opposed to that of men’s. Any surgery around this area affects the delicate tissue and nerve endings. Breasts and nipples are acutely sensitive to touch so the cutting of these delicate tissues causes painful symptoms in women. There is no doubt that these symptom experiences influence how women perceive themselves after heart surgery, and it effects how they are ‘supposed’ to appear in society. Women’s breasts are a fundamental to their identity in many ways.

Figure 8.1: This painting called Kia U by Robyn Kahukiwa depicts the links between hearts, breasts and the womb (Kahukiwa, 1995, p. 6)



Breasts are the source of nourishment for successive generations; they are part of women's femininity and sexuality. It is no wonder that, one of the woman participants found new clothes to conceal the scar.

### **Caring about others**

Alonzo (1986) has peripherally mentioned coverage of relationship obligations where people wish to stabilise their symptoms in order to remain involved in their daily situations and mobilise resources to contain symptoms within a socially defined situation. Schoenberg and colleagues (2003) use a more comprehensive term, which is competing social demands. It is described as "Participants often indicated that important activities and responsibilities may prevent or forestall formal medical presentation, specifically discussing how they often overlooked or tried to ignore bodily sensation because of work, family or social responsibilities, since formally

treating such symptoms failed to 'fit' into their lives" (Schoenberg et al., 2003, p. 275).

### ***European and Maori women***

In the 1960's information about heart disease stressed that women must take care of their spouses heart disease (C. L. Miller & Kollauf, 2002). A woman participant had gone to the doctor to sign some papers but not mentioned her own health. Information for women's heart symptoms does not bear any relationship to their social situations. The realities of women's lives within the family, and wider community are that they care for others ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000; Mosca et al., 2004). In the most extreme case it showed how women are socially conditioned to put others needs before their own. A woman participant, who put off getting help, then summoned the ambulance and sent it back to base, because caring for her daughter's welfare was her main priority. It did not enter her head that she may die from her heart symptoms. Another woman put off getting help for symptoms until she reached the point of collapse because of the embarrassment of being a burden to her family.

Schoenberg's and colleagues (2003) category describes a familiar dilemma for women. Women put themselves last (Oakley, 1976, 1981). Competing demands describes Maori women's social dilemmas where they still have to provide for, and financially support a wide group of whanau members. They are expected to carry out their traditional duties (caring for grandchildren, etc.) in households that have a much lower income threshold than those of European women. To accomplish this they put themselves last and put off seeking medical care until they are forced to get help (M. Durie, 1994; Walker, 1990).

### ***European men***

For European men the social situation was different, they did consider others but also expected help from women in their family. Or men expect women to take some action. Alonzo (1986) notes that initially most people decided to seek the advice of their spouse (90% (N=477) compared to 56.1% (n=234) from family and 69.8% (n=171) from workmates, neighbours and friends.

### ***Maori men***

Maori men acted out their care for others using their cultural concept of mana to make decisions, which incorporated their personal identity as leaders of their extended family and their obligations to provide for the extended family. Sources of power and authority in Maori tradition came from the gods or atua. Mana is the Maori word for power or influence. There are four interpretations of mana in Maori society: Mana atua is power and authority from the gods, mana tangata is human power through inheritance or skills, mana whenua is the power to exercise territorial rights within the tribe (iwi) or sub tribe (hapu) and mana Maori is minimal political power for Maori through exclusion from government consultation processes. Maori men were customarily pronounced tapu (sacred) when they prepared for battle. This custom was designed to ensure that men were psychologically prepared for the battle, their attention was focused and their anxieties were reduced. An important part of their role was to bear the pain of battle wounds with pride and long suffering dignity.

One man carried out his economic obligations when he sold four bags of mussels at the market before deciding to return home. His actions demonstrate that he maintained his mana through bearing painful symptoms until he could fulfil his obligation to financially provide for his whanau. This example shows that self-regulative processes are culture bound. This man's experience illustrates the link between cultural concepts that affect cognitions. These actions result in behavioural outcomes where normative beliefs differ among women and men within distinct cultural frameworks (Ciofu Baumann, 2003; H. Leventhal et al., 1997).

### **Summary**

This chapter has covered the discussion of how 'people have different ways of enduring symptoms'. First of all the chapter covered how European and Maori women use strategies to cope with the pain of childbirth to relieve symptoms. Women endured symptoms while they support their spouse. Women's guilt at having painful scars after heart surgery is explained. Maori put obligations to their whanau members before their painful symptoms, which is discussed in terms of women's responsibilities and men's mana or authority. The second part discusses the methods that women use to cope with painful symptoms together with a discussion of how

much influence caring for others in the social network contributes to prolonged delays. Then the discussion examines how caring for others motivates women, men, and Maori to conceal their symptoms while continuing to uphold the needs of others. This chapter has identified how people endure their symptoms, which informs the findings in the last results chapter (Chapter Nine) by creating the justification for participants' reasons for obtaining reassurance.

## **CHAPTER IX: RESULTS**

### **REASSURANCE FOR SYMPTOMS**

*I believe in the equality of the sexes. I truly believe that men are just as equal to women in the work they do. I believe that a man is as good as a woman and that a man should have equal chances with a woman.*  
Mabel Howard, Trade Union Secretary, Labour MP and Cabinet Minister, speaking in Parliament in 1953 (*Quotable New Zealand women*, 1994)

#### **Overview**

This chapter has four main sections. The first section, Part One, reports the findings from the category ‘people obtain reassurance in different ways’. There are several ways that people obtain reassurance from family discussions to medical consultations and received a misdiagnosis, which was not disputed at the time. The second section, Part Two, covers the findings from the category ‘people take action in different ways’. This section elaborates on how people endure their symptoms before seeking the comfort and reassurance of others in their immediate social network. The two categories are: (a) People obtain reassurance in different ways and (b) People take action in different ways. The third section contains a summary of the key original findings together with illustrations of the model of responses to heart symptoms, and the model of theoretical underpinnings related to the self-regulatory model. In the final section there is a discussion about different ways of obtaining reassurance about symptoms, how people carry out self treatment strategies, how people perceive their doctors, how age influences consultations with doctors and interactions between the participants and their doctors.

#### **Part One: People obtain reassurance in different ways**

##### **Introduction**

Participants did not make the decision to get help for their symptoms until they had consulted someone in their locale. The category pertaining to reassurance was a key factor that impacted on care-seeking actions. The act of obtaining reassurance runs

through a gamut of interactions from discussing things with family or whanau, or if experiencing acute symptoms in a public place relying on strangers. Seeking reassurance from doctors led to differences in the language used to discuss symptoms, difficulties recognising women's symptoms and diagnostic confusion when other chronic conditions were present.

The symptom descriptions in Chapter Six show that symptoms vary between individuals and change in meaning and importance as the social situation changes. Symptoms can shift from simple body sensations and be re-evaluated as a recognised problem that requires some kind of action. This process is not just a single starting point with a predictable end. It is a cyclical process where bodily wellbeing is scrutinised daily as people carry out duties subscribed within their social roles. Perceptions about symptoms arise out of the participants' lived experience in a wider sense that includes feelings and cognition. Symptoms are recognised, appraised and labelled according to a range of cognitive factors. Mental representations of symptoms include beliefs, gender, cultural identity, social norms, values and the expectations or consequences of the symptom within the social milieu. It is not surprising then that participants sought comfort, reassurance, support or advice from people who were close to them or in the vicinity at the time of a distressing symptom episode or an acute event. Participants did not make the decision to get help for their symptoms until they had consulted someone in their locale.

The category pertaining to reassurance was a key factor that impacted on care-seeking actions. The title 'people obtain reassurance in different ways' replaces an earlier category term communication, as it was too restricted to describe the range of complex interactions triggered by symptom experiences. Participants carried out a range of different activities to seek reassurance for symptoms that had 'broken through' their individual attempts to relieve or control them. The act of obtaining reassurance means that participants consult with others to dispel their fears or to seek confirmation about their symptom experiences. The rationale for this theoretical code has been derived from the data provided by participants. Terms contained within the category are defined as:

Obtain - acquire or have granted (Fowler & Fowler, 1962, p. 701).  
Reassurance - restore confidence, dispel apprehensions, confirm opinion or impression (Fowler & Fowler, 1962, p. 701). Family - all descendants of a common ancestor, members of a household, a set of relations living together or not (Fowler & Fowler, 1962, p. 349). Whanau - extended family, hapu or iwi (M. Durie, 1994, p. 70). Friend - one joined another intimacy and mutual benevolence independent of sexual or family love (Fowler & Fowler, 1962, p. 394). Consulting doctors - to seek information or advice from a physician (Fowler & Fowler, 1962, p. 202).

***Participant data - People obtain reassurance in different ways***

This category is a combination of three important needs that people have when experiencing the distress of painful or worrying symptoms. The category label means that people seek comfort, advice and support from other people in order to relieve the symptoms, or to take control and survive the symptoms. By interacting with other people in their support networks, participants have acquired the confidence to cope with symptoms, reduced their apprehensions about the potential consequences of symptoms through engaging with social support. The concept 'people obtain reassurance in different ways' covers a range of interactions within the social context of symptom experiences. These include: obtaining reassurance from family, whanau, friends, or fellow passengers, and consulting the doctor for reassurance about symptoms, or consulting the doctor for reassurance and receiving an initial misdiagnosis, or not being referred for cardiac intervention as well as how Maori men seek reassurance for other chronic health conditions.

The following participant data describes the types of reassurance that participants' believed would support them at the time. The most common form of reassurance was consulting with family or extended family members living in one household. Three situations unfolded in participants' recounts of their symptom experiences where family members were not able to be present. One acute event occurred in a hospital and a friend helped by calling for medical staff.

### ***Reassurance from family***

This category means that people consulted their families for comfort, support and advice when the symptoms became painful or distressing. After experiencing initial heart symptoms women were uncertain as to the cause of their health problem. They did not connect the symptoms to heart trouble. Instead they attributed their discomfort to a range of causes. Women sought moral support and assistance by discussing their symptom experiences with family. Younger women participants engaged the help of their spouses for clarification about symptoms. The spouses suggested a visit to the general practitioner. It did not occur to spouses that the symptoms were serious enough to contact emergency assistance.

*I talked to my husband. He said, oh, have you eaten a big lunch or something because that can happen, indigestion. Well I don't suffer with it, he does, I don't so. I said to him perhaps it is being in the country (inferring an allergy)*  
(European woman, Office Clerk – 57 years)

*I got a heavy feeling in the middle of my chest again but I still didn't think about it being ...I was getting very short of breath and puffing. My husband said well shall we take you to the doctor. I said well ring the doctor ...Then he rang an ambulance.* (European woman, Company Director –58 years)

While older retired women were more likely to live alone or be living with family. This retired woman was confused about her symptoms, perceived them as brought on by overexertion or indigestion. Her description of the symptoms was vague, using indirect terms ('nodding off') and attributed them to fatigue when informing her daughter. It was only when she collapsed that her daughter took action and called the emergency services.

*I kept saying that I've got to nod off for a spell. Fortunately my son and daughter in law were there on the spot straight away because I'm staying with them and they called the ambulance.* (European woman, Retired – 75 years)

In this woman's case she discussed her tiredness with her daughter and the ambulance services. At the time she remembered a friend's advice but she became confused

about her symptoms because they were not similar to the sensations of a palpitating heart. Eventually she contacted emergency help and continued deliberating about the cause of her symptoms.

*I said to (daughter) I think I will ring the St John's Ambulance for advice because they are very good ... we will send somebody out to you. I said I would appreciate that because I have never had anything like this before its very odd and I can't give in to my great tiredness...Something very funny happening here. (European woman, Retired – 78 years)*

Symptoms of burning pain: *get this burning pain, fatigue, I've got to nod off for a spell, or shortness of breath, I was getting very short of breath and puffing, and an allergy, perhaps it is being in the country,* were the triggers for getting help from family members. The symptoms were attributed to exhaustion or discomfort and communicated to family as tiredness. During this time participants and family members did not recognise the symptoms as heart related. Therefore, the symptom language elicited a response that was perceived as appropriate for mild symptoms thus creating long delays before summoning medical attention.

### ***Seeking reassurance from whanau***

This category means that Maori sought reassurance, comfort, support and advice for their symptoms from spouses or extended family. Two Maori women described how they obtained support from whanau when they were experiencing symptoms. The first woman recognised that her symptoms may be a heart attack. Even though she recognised the symptoms as serious she went to her spouse and they felt comfortable about travelling to the large clinic by car.

*I said to my hoa (friend) – my chest and then I came out, he was with me ... I said, I think it might be time for you to take me straight down to the (Clinic) because I think this is more than heart burn. It might be a heart attack. (Maori woman, Retired – 66 years)*

She had not thought of contacting the emergency services when the Maori interviewer asked her about the way she got to hospital

*Well, I didn't think of the ambulance because my husband was there. (Maori woman, Retired – 66 years)*

Another Maori woman experienced angina symptoms. She told her spouse about her distressing, painful symptoms and they drove up to the medical clinic.

*Tight in the chest. Right across. Bending over and sort of holding my chest. Didn't know where (indistinct), I went and lay down and I didn't know how to lie, whether the side or back or the other side. I started moving around again, in the end I told my husband and he said to ring when he saw my face was white. (indistinct) make our way to the medical clinic. (Maori woman, Sickness Beneficiary – 64 years)*

In these two cases the women were experiencing severe symptoms *bending over and sort of holding my chest* and *when he saw my face was white*, which were recognised as serious by partners through the amount of physical distress that was exhibited at the time. One woman was doubled over in pain and used the Maori term for friend *hoa* when describing events. The other woman's face had lost colour. During these acute events there was no distinct description of the symptoms. The account of the acute event was related to the interviewer interspersed with a pattern of indistinct language. One small clue about the comfort that family provided was denoted by the reference in Maori, *hoa* (friend) for a partner.

This man describes calling in to his sister's home and then feeling sick. Whanau members voiced their concerns about his state of health. Then they offered emotional, spiritual and practical support and a place to stay. His brother and sister gave him a carved *tokotoko* (carved walking stick) to keep beside him during his illness. His family recited a *karakia* (prayer) before he continued his journey back to his home in the city. The presentation of the *tokotoko* provided symbolic reassurance, love and help from his family because he was ill.

*we stopped at my sister's house in (town) on the way home to ...(city), and we had a big kai (meal) there. And not long after the kai I went out the back of*

*her garden and I, and I brought it all up. And I knew I was sick. They all come out to see what was wrong and I said, No, I'm alright, I'm alright. No, you're not. You stay here tonight. No, I'm going home to (city) Oh, I don't know how it, how to explain it to you because um I used to see Dad with it (carved walking stick) all the time and then Dad passed away and my brother and our sister keep it in a korowai (a chiefly tag cloak) in (town) and when any of us get sick they make us take it to just keep it with us just to help us. It's got canoe names on it. Well my brother and my sister gave it, told me to take it. ... And she done me with water after I got sick. (Maori man, 54 years – Labourer)*

After the family had provided the meal and discussed his illness they did what they thought was important to protect him to ensure his health and wellbeing for the journey home. Even though this man had been offered support, was exhibiting severe symptoms and feeling unwell he decided to drive home.

Two Maori women felt more comfortable discussing their symptoms with spouses, *I said to my hoa (friend)*, and then travelled to clinics by car, *I think it might be time for you to take me straight down to the (clinic)*, with family support to seek medical help. One man sought and received a wide range of help, *and we had a big kai (meal) spiritual, and when any of us get sick they make us take it to just keep it with us just to help us*, deemed appropriate by his whanau and an offer of accommodation from his immediate whanau, in spite of this assistance he continued his journey home.

### ***Reassurance from friends***

This category means that people experienced symptoms in the presence of friends who reassured them and obtained help. In this woman's case it was fortunate that the acute symptoms occurred in the hospital where she was employed so it was easy for the friend to obtain medical attention. She described how she got reassurance and support with her premonition of a brush with impending death. The following scenario describes how this participant faced a frightening experience supported by her friend. When she felt the symptoms, she refused to face them alone. This episode shows that people do react to obtain support and reassurance, which was, for her, survival strategy when experiencing severe symptoms.

*I was coming upstairs and the walls seemed to come in on me. No chest pain as such and I remember (name) my friend and I said come here Anne and hold my hand and don't let go. You know that story about going backward through a tunnel I said (name) don't let my hand go or I'll be gone. (European woman, Retired – 76 years)*

Often older women who live alone and are in poor health are socially isolated. This participant was supported by her housekeeper (who cleaned her house on a weekly basis) during her first episode of angina. This particular woman had a medical history of being highly anxious after the death of her husband in hospital after his fatal heart attack. She did not have the confidence to cope with her symptoms and was too distressed to deal with her symptoms alone. After the angina diagnosis she rang her friend for reassurance instead of calling the ambulance.

*Yes, I had a lady help and she was the one that actually put me in the car the first time and took me to the doctor. (European woman, Retired – 75 years)*

One woman obtained prompt medical help when her friend was about to collapse, stating that: *the walls seemed to come in on me*, while she was at work in the hospital. Another woman had discussed her pain with her housekeeper: *she was the one that actually put me in the car*, and both of these women had not recognised the heart symptoms initially.

### ***Consulting the doctor for reassurance about symptoms***

The following table compares symptom descriptions from participants and the written comments from medical records. Table 9.1 illustrates the different language and interpretations of symptoms between doctors and participants. Some of more noticeable differences are that pain in the tops of arms was interpreted by the doctor as shoulder pain, burning pain was recorded as chest pain, shortness of breath was recorded as chest pain. In some diagnoses only one symptom was recorded which was the chest pain and other symptoms such as blurred vision and perspiration were not. Symptoms were not recorded correctly when there were differences in

perceptions of severity. For example, when the participant reported severe chest pain the doctor recorded it as mild chest pain.

In Table 9.2 some of the participants mentioned fatigue and this was not recorded as a symptom. One doctor had recorded that the participant had denied his symptoms. Another doctor had thoroughly recorded every symptom mentioned by the participant and other recordings noted heart rhythm changes but participants had not reported this as a symptom. Only one doctor had reported a vague description for chest pain.

***Consulting the doctor for reassurance and receiving an initial misdiagnosis or not being referred for cardiac intervention***

This category means that women consulted their doctor for reassurance about their state of ill health and were misdiagnosed or not referred to hospital for further tests. This woman visited her doctor regularly, when she told her doctor about her fatigue, the doctor did not relate it to fatigue induced by symptoms of heart disease. The doctor's response was dismissive and she agreed with him. A few days later this woman rang the emergency services for advice at the time she was experiencing acute, painful symptoms. During this acute event she delayed getting medical attention from just after lunch (about 1.00pm) until dinnertime (about 5.30pm). She would not allow the ambulance to come until later that day, after she had arranged care for her daughter who had a psychiatric condition.

*I was desperately tired all through lunch. But, Dr (Name) will tell you that I tell him when I sit down to read the paper with my cup of tea and rest my eyes and wake up two hours later... his comment to that was "its nothing new is it", (laugh). (European woman, Retired -78 years)*

Another case of misdiagnosis is where the woman got to her local doctor and her previous diagnosis of high blood pressure was checked. She was sent home and informed that she could have her blood pressure checked in, *a couple of days*. At the time, her symptoms were not perceived as serious enough to warrant an electrocardiogram (ECG). Later that evening she was driven to hospital by her husband and admitted with an acute myocardial infarction.

*I was taking Mylanta (indigestion remedy) of all things. Ohh I didn't feel well so I called in to doctor and um the blood pressure was up everything was up he says ohh come back a couple of days and we will have a check of that.*  
(European woman, Retired – 73 years)

**Table 9.1: Differences in symptom descriptions between doctors and European participants**

<b>Doctors</b>	<b>European Participants</b>
Chest heaviness Chest pain radiating to left and right shoulders Short of breath pale pulse good but irregular Central Chest pain cold clammy skin Nausea Feeling unwell (Hospital)	Tops of my arms started to ache - heavy feeling in the middle of my chest (Woman)
Central chest pain radiating through back (Hospital)	You will get a burning pain (Woman)
Developed chest heaviness radiated to left arm and wrist associated with nausea and sweating (Hospital)	I felt a pain in the centre of my chest accompanied by coughing and feeling a bit clammy (Man)
Retrosternal chest tightness radiated to both arms (Hospital)	I felt pains from one side of my chest to the other, not excruciating, more constriction than sharp pain. I thought that's odd, (Woman)
Onset of severe chest pain (Hospital)	I though oh no I'm a bit short of breath and I seemed to be very hot and quite moist around the skin surface (Man)
Pain in centre of chest area (Hospital)	I got a sore arm. A sore left arm and I got a pain up in the middle of my chest (Man)
Constant coughing No chest pain No angina Advised GTN and call Ambulance (GP)	I couldn't believe that a man who specialised in hearts and I presume he does – I thought well if he doesn't know about that- no pain- and I thought I had described it reasonably well – I've asked him and got nowhere (Woman)
Chest pain probably angina (General Practitioner)	A slight tightness in the chest (Woman)
Dull central chest pain (GP)	Blurred vision and the tightness of the chest and the perspiration (Man)
Chest pain and tiredness (GP)	A burning sensation across my chest (Man)
Heart burn accompanied an irregular heart beat (GP)	I didn't have any pain, I felt this chest thing It wasn't a pain I couldn't bear it was constantly being uncomfortable (Man)
Central chest pain? mild angina (GP)	I had a soreness in my chest area, it wasn't a pain (Man)
Mild angina pain (GP)	Severe chest pain down both arms, sweating and up my throat (Man)
Angina pain (GP)	As though I am being squeezed on both sides – the pressure (Woman)

**Table 9.2: Differences in symptom descriptions between doctors and Maori participants**

<b>Doctors</b>	<b>Maori Participants</b>
IHD no symptoms (GP)	I just went straight out (Man)
Tired short of breath (GP)	Around the chest ah yeah you get sore heavy (Woman)
Chest pain difficulty breathing (GP)	Its mainly shortness of breath and very tired (Woman)
Denied symptoms Right side of chest hurts Unstable angina (GP)	Tight in the chest, right across didn't know where (indistinct) too uncomfortable to lie down (Woman)
Asthma Bronchitis (GP)	Sort of just around the heart (Man)
Atrial flutter not compliant with medication Chest pain chest tightness (GP)	Largely the sharp pain on one side and on the left side of the chest very sharp pain like swelling in the ribs
Left shoulder and central chest pain (Hospital)	Collapsed (Man)
Central chest pain radiating to arms and back, no shortness of breath, no nausea, no sweating (Hospital)	A bit of discomfort in the chest (Woman)
Chest pain (vague) Short of Breath (Hospital)	I was feeling a little not too well I had pains (Man)
Sudden onset of chest pain then in jaw and left arm, became sweaty then nauseous, short of breath, skin pale colour, previous symptoms 1 week ago (Hospital)	It was a burning sensation in the chest It was really bad and then it slowly went up to the jaw, the neck the jaw it started getting really sore and then I just started sweating (Man)

In this symptom episode this woman conveyed her discomfort to the doctor who passed off her continuing symptoms as being related to elevated blood pressure. The doctor diagnosed the high blood pressure but did not connect the vague symptoms with an acute event, such as angina or a heart attack. In this woman's case, the general practitioner had treated her for angina over a lengthy period. She was at home when she experienced an episode of acute pain and one of her children drove her to hospital. She was dismayed and angry that the doctor had not considered her heart disease serious enough to warrant an angiogram or further cardiac intervention. In her view the serious heart condition could have been diagnosed earlier. So the doctor had not lived up to her expectations of reassurance.

*And I was still having angina and I was back at home and I started going into the angina phase... and the kids said you look shocking Mum we are taking you to (hospital) they said surgery as soon as. I could have had that operation*

*earlier on instead of going through all this extensive body surgery. Why didn't someone pick it up earlier?* (European woman, Retired – 76 years)

One woman had consulted her doctor with symptoms of fatigue that was discounted and she was sent home without further investigation, *I get tired so his comment to that was its nothing new is it.* A second woman who attended her local clinic for regular blood pressure checks was sent home without investigation, *he says ohh come back a couple of days.* The third woman became angry when she realised that her doctor had not referred her to hospital for further surgical intervention, *they said surgery as soon as.* She had endured a lengthy period of painful symptoms that virtually disappeared after receiving heart surgery.

### ***Women with uncommon symptoms were disregarded***

When three women visited their doctor for reassurance because they were uncertain about the nature of the symptoms - the symptoms were disregarded. Three women described atypical heart disease symptoms. One woman experienced a fullness in her rib cage, but no pain, another woman described a similar full feeling and felt generally unwell, while a third woman described herself as puffed or short of breath and unable to perform any physical activity. All three of these women regularly visited their doctors and their queries about symptoms were discounted.

*I don't get much back from – well doctors are seeing it all the time and they Its just that the time I asked Dr (Cardiologist) I had no pain – I felt that my rib cage was just full of lungs and hearts and everything....So I did that and I said “do you know what I mean” he said no. I said it doesn't ring a bell? “No” OK. So that was that. (laughter)* (European woman, 78 years- Retired)

*I'd been very puffed just everything. Just trying to do the luxing, just getting up the stairs. It was getting tooo much I had to really force myself to (Emphasised words here) To do anything.* (European woman, 73 years Retired)

The first woman sought information about her symptoms from her cardiologist about her symptoms but as the conversation illustrates her cardiologist did not attempt to

clarify the origin of the symptom, *I felt that my rib cage was just full of lungs and hearts and everything*, or provide any further information the about the symptoms she was experiencing. This woman implied that this was an expected response from doctors. Another woman was upset about her symptoms and conveyed her distress by talking loudly, *I'd been very puffed just everything it was getting tooo much*, about the symptoms. These women were feeling generally unwell, fatigued and experiencing significant discomfort. However they did not recognise that the bodily sensations were due to heart symptoms.

### ***Maori men seek reassurance for other chronic health conditions***

This category means that Maori men and doctors became confused as to the cause of the symptoms. The reality for Maori is that they frequently suffer from more than one health condition. The following cases demonstrate that heart symptoms are experienced in conjunction with other conditions such as diabetes or asthma. This particular symptom experience lasted three days. This man had a history of asthma. After the death of his brother, he took up smoking again. A few days before he went to his clinic, he had felt tingling pains in his arms and a sore chest that he thought was indigestion. He went to his doctor who treated him for indigestion. He went away for the weekend, felt unwell and drove home against the wishes of his whanau. He believed that he was suffering from asthma. Upon his arrival at the medical clinic he was treated immediately for asthma. His symptoms were not relieved by the nebuliser so the doctor took a blood test, diagnosed a heart attack and summoned an ambulance that took him to hospital.

*Little bit of tingling – not, not much, but just a little bit down the arms. It was in my chest -It was like as if I had um indigestion. And um I told them it was indigestion and then they, they gave me, they gave me some white fluid to drink,....Soon as I got there they put me on the nebuliser at the medical centre. ....They took blood off me and um after about three quarters of an hour that's when they come back and told me that I had had a heart attack. (Maori man, 54 years-Labourer)*

In the second case, this man had suffered from diabetes, asthma, and congestive heart failure over a five-year period. His symptoms were interrelated as coughing with

asthma brought changes in bodily sensations in his chest and heart rhythm. He described how he had slowed down as a result of his illnesses.

*As if to say you've got cramp That's how I know I get a pain in the chest, in the heart, a swelling. I've got diabetes, as well as asthma. And those two kind of (indistinct) the heart, that's what it does, just makes your heart dysfunction.* (Maori man, Sickness beneficiary – 61 years)

The presence of more than one health condition: *if I had um indigestion, They gave me some white fluid to drink, or they put me on the nebuliser*, can result in both doctors and participants being unsure about the cause of symptoms. An example of suffering more than one health problem is: *I've got diabetes, as well as asthma*. When people are coping with symptoms of more than one illness it contributes to confusion and results in prolonged delays in reaching hospital.

### **Summary**

There were many ways that the participants sought reassurance. Reassurance emerged as an important step in coping actions to relieve symptoms. It took many forms including seeking emotional comfort and practical support from immediate family, such as spouses. Then there was an example of Maori interactions with whanau (extended family) who provided spiritual, emotional and practical support for their sick whanau member. Also there were the times when acute symptoms occurred outside of the home and reassurance and help was sought from a friend and fellow passenger. Consultations for reassurance and information about symptoms had different outcomes. The difference between medical records and participants' symptom descriptions showed communications about symptoms are interpreted according to doctor's perceptions. Medical consultations for women did not always produce the reassurance that women participants wanted. These consultations included dismissive reactions from doctors about women's uncommon heart symptoms. Consultations with multiple interactions between the woman and her doctor resulted in not being referred to a tertiary centre for further investigation. Maori men's consultations revealed that they did seek medical help but the presence of other chronic conditions masked heart symptoms.

## **Part Two: People take action in different ways**

This section covers how people carry out coping strategies for symptoms. The label for this category, 'people take action in different ways' replaces an earlier term 'everyday coping strategies'. The label means that participants used familiar procedures to cope with their symptoms. It also means that participants chose actions according to how acceptable their actions were to people in their immediate social context. A further meaning is that participants used the most socially acceptable ways of getting help. If symptoms became severe they did take actions that may be unacceptable or have negative consequences. These procedures differed according to whether the participant was a woman, a man or of Maori descent. Procedures were chosen according to perceptions about the seriousness of symptoms, and perceptions about the positive or negative consequences that impacted on close relationships surrounding symptom experiences. The dictionary definition of actions is:

Actions means "the process of action, exerting energy or influence (Fowler & Fowler, 1962, p. 10).

Actions can have positive or negative consequences that are sanctioned or rewarded by the attitudes and actions of people within the adjacent social context.

### **Participant data - People take action in different ways**

#### ***Women care for others before they seek medical assistance***

This category means that women cared about family members welfare before themselves. Another meaning is that women ensured that family members were not disadvantaged or disrupted if they left the home to obtain medical care. Women's roles impact on the actions that they take to get help for painful symptoms. This retired woman had a major responsibility caring for a sick daughter. In this case the woman summoned the emergency services then sent the ambulance away until she had arranged care for her daughter who had a chronic mental health condition. Another problem was that the ambulance attendants appeared confused about the symptoms and did not perceive that she was having a heart attack. So the woman

made arrangements for her daughter and did some packing before calling the ambulance again. She eventually got hospital care later in the evening.

*I said yes I would love to go into hospital please and just find out. First I have to get someone to look after my sick daughter I can't just leave her. They said we will go back and if you get worse ring us and as soon as you can come ring us and we will take you to hospital. As soon as they had gone (daughter) said Oh don't leave me Mum, don't go to hospital. This is the whole thing with her I'm her big comfort station and she needs me 25 hours a day if that's possible. Then I thought right and rang the ambulance and said I'm ready now I'd like to go to hospital please. They said right and round they came and (daughter) was there with (sick daughter), and (sick daughter) kept saying don't go Mum don't go, don't leave me. (European woman, 78 years - Retired)*

This woman reflected on her symptoms of chest tightness and put it down to age or overwork. So she reluctantly went to see her doctor after asking her husband to approve her decision to seek medical care. She was thinking of her list of tasks. These duties are related to the double burdens women have with obligations to work and family. Double burdens for women are considered a risk factor for heart disease.

*if you do as much plus work full time and do everything else that you can't do it all. Well I work full time, I'm a fanatic gardener. I have done all the decorating and done the gardens from scratch, helped concrete. (European woman, 57 years – Office Clerk)*

This woman considered that it was permissible to contact her daughter to get some pills to relieve her symptoms but she did not feel confident enough to contact her doctor. When the daughter arrived she contacted the receptionist for her mother's doctor. When her daughter wasn't satisfied with the advice from the doctor's clinic she made the decision to call for an ambulance.

*I said to her ring my doctor's surgery ... she did get somebody who wasn't really medical, she was in the office so I heard ...(her daughter) say blow that and she dialled the ambulance. (European woman, 79 years – Retired)*

In this next scenario the woman did not consider that she was under pressure. She felt that her spouse was more likely to take the strain of the business. But as she explained about her numerous roles, doing the business paperwork, running a home and catering to the needs of seven grandchildren it is obvious that she was under pressure from multiple roles. She only alludes to her heart attack by admitting that her work and family responsibilities must affect her. It was her spouse who finally rang the doctor to get help for her painful symptoms. At no time did they consider that she might be having a heart attack.

*I was getting very short of breath and puffing. My husband said well, shall we take you to the doctor. I said well ring the doctor ...Then he rang an ambulance and the ambulance came straight away. Yes we have seven grandchildren. They all arrived virtually together. The oldest one is only six. ...and when they come here they stay with us, which is very tiring. (European woman, 58 years – Company Director)*

This woman felt that she would be bothering her family who lived with her if she asked for help to deal with her symptoms. After being hospitalised for a heart attack she reflected that sometimes help is necessary.

*No the only thing that went through my mind was that I needed help and was I just being a nuisance. But you are never a nuisance when you need help. (European woman, 75 years – Retired)*

European women had several reasons underlying why they delayed taking action about their symptoms. One woman went through a protracted decision making time while she sorted out her daughter's care, *she needs me 25 hours a day if that's possible*. Another woman's thoughts about getting help for her angina pain were coloured by her reflections about her multiple tasks, roles and responsibilities at work and in family life, *if you do as much plus work full time and do everything else that you can't do it all*. Another woman found it permissible to talk to her daughter about her symptoms when the daughter rang. She felt comfortable about her daughter contacting the doctor to obtain pills but not about getting an ambulance to hospital.

One woman did not consider herself to be at risk of a heart attack brought on through balancing business worries and family responsibilities, *when they come here they stay with us, which is very tiring*. One woman did not want to be a nuisance, *was I just being a nuisance*, to her daughter when she was sick.

### ***Maori women often have experienced chronic health conditions***

This category means that presence of other medical conditions can be confusing when intermittent symptoms are experienced. This woman felt that it was permissible to contact her nurse at the Health Trust because it was an established and routine part of her diabetic medical care.

*Mostly I think of my sugar diabetes, you know, most of it now. But since I been here in this unit, (indistinct) ...(nurse) there to look after me and if I want anything I send for ...(Nurse).* (Maori woman, 72 years – Retired)

*Could feel it, the pain. But when I rub it, I, it seems to help, you know. .. so I went to the doctors and that was when he found out. He said my heart was enlarged.* (Maori woman, 72 years - Retired)

She raised important concerns for Maori, which may be barriers for getting to medical clinics. Her perception was that the doctor was good, that she was not expected to pay the doctor and because of this, she was able to afford to pay for her medicines.

### ***Men's commonsense response to symptoms***

This category means that men carried out actions that were a sensible response to an episode of angina. This man describes his visit to the clinic as natural or commonsense thing to do. He did not use many word to describe his perception of a straightforward action. It is easy to see that his attendance at the clinic and his subsequent treatment was the result of predictable expectations. He expected his symptoms to be angina because his friends had suffered from it. The staff listened to his explanation; they diagnosed heart problems and prescribed the appropriate treatment.

*It was just a natural thing to do. Oh I just explained exactly what happened. They sounded my heart and things like that; they gave me a sublingual spray and gave me some heart pills. (European man, 80 years – Retired)*

He did not stop to consider other roles or responsibilities and the outcome of heart disease didn't appear to surprise him, *it was just a natural thing to do*. His experience is a sharp contrast to the European woman who went through many decisions about responsibilities and some confusion about her symptoms before ending up in the emergency ward.

### ***Maori men hesitate to take action***

This category means that Maori men are very reluctant to take action about symptoms that may result in a hospital admission. This Maori man did not allow his wife to ring for an ambulance when experiencing heart attack symptoms. He attributed his symptoms to indigestion. After his symptoms did not abate his wife rang the ambulance.

*I just told the wife, cause she wanted to ring the ambulance, and I just told her it was, ah, just indigestion and it would go away. She just rang an ambulance and told them to come and get me.*

(Maori man, 46 years – Labourer)

This man's case shows that he was in agony but still refused to go to hospital. He believed that the symptoms were caused by indigestion at the time. He was taken to hospital by ambulance and admitted to hospital for a first heart attack.

### **Summary**

This section covered the category related to taking action to get for distressing symptoms. Women put the welfare of other people before their own health. One woman went to extreme lengths to get care for her daughter before getting medical help. Another woman treated herself at home with massage and rest before visiting the doctor because her other chronic conditions had caused confusion about the cause of her pain. A Maori man had left it to his spouse to take action and summon the

ambulance. The next part outlines the theoretical models developed from the findings.

## **Summary of key findings**

‘Recognising Women’s Responses to Heart Disease Symptoms: Different groups respond in different ways’ is a concept that paves the way for new approaches to community based education about chest pain and heart attacks. The findings are summarised in two parts. Part One reports the key findings that are consistent with the literature from previous research and part two discusses the key original findings.

### ***Key findings related to the existing literature***

There were reasons for delay in seeking care for heart disease symptoms common to all study participants that have been well documented in the literature. These reasons were: difficulties recognising heart disease symptoms, self treatment to relieve symptoms, obtaining reassurance from family, or friends and consulting general practitioners. Some European women, who reported uncommon symptoms, received an initial misdiagnosis from their general practitioners and this finding has been reported in the literature. Maori women and men minimised their symptoms and were reluctant to discuss them, which has been previously reported in the literature. Maori were more likely to consult with (whanau) extended family, which has been discussed in the literature, but not specifically in relation to care seeking for heart disease symptoms. The study findings based on participants’ perceptions have shown that new paradigms to tackle the global phenomenon of ‘patient delay’ can provide vital information that health providers habitually overlook. There is still a place for traditional, generic, population based programmes in health promotion, secondary prevention or cardiac rehabilitation. The blanket coverage (population based approaches) of public education for obtaining prompt emergency help for heart attacks has not been successful. Researchers need to be more responsive to women’s particular needs and acknowledge the differences in symptom presentation between women, men and Maori. Researchers need to engage in new ways of thinking, as there is a need for new approaches to delays in seeking care for heart disease symptoms that includes lay people’s perspectives.

### ***Key original findings***

The theoretical concept derived from lay people's symptom experiences build on existing knowledge and practice by using as a base the self-regulatory model of illness perceptions (H. Leventhal et al., 1997). This model has been used to identify the processes surrounding people's beliefs about symptoms, which drive coping strategies. The model has been empirically validated as previously mentioned. Several, additional, behavioural rules have been identified within the model, that demonstrates how people's perceptions of their symptoms, can be mediated by age or stress (E. A. Leventhal & Crouch, 1997). The researcher has identified a further set of cognitive rules (Argyle & Henderson, 1985) that can be linked to the self-regulatory model of illness representations (H. Leventhal et al., 1997). These rules helped participants determine what actions were acceptable or unacceptable. The rules were social constructions that were different for women, men and Maori according to each particular social environment. It is through these rules that the socially constructed nature of care seeking is rendered more explicit. The outcome of care seeking depends on illness beliefs and the influence of relationships and interactions in the social context.

Whether the person is a woman, a man or Maori they will weigh up the consequences of causing disruption in their social network. Assessment of the symptoms and the consequences that impact on significant others predisposes people to take actions that elicit unspoken approval. An example of these actions, could be, that a woman copes with symptoms by resting and concealing them from others because a visit to the doctor may cause an unexpected expense for family. Acknowledging that her symptoms required medical assistance might expose her to the criticism or disapproval of her spouse or children for spending meagre family funds. Mild or intermittent symptoms might be endured for lengthy periods because a woman may have fears about her doctor's attitude. For instance, the doctor may think that she has anxiety problems because she constantly complains about fatigue, which she thinks that the doctor is not able to fix, or that she is taking up too much of the doctor's time.

*Recognition of heart disease symptoms by women and their doctors is vital.*

Health providers need to recognise women's angina or heart attack symptoms. Until recently, women and their risk of heart disease has been a well-kept secret, cloaked by

the assumptions of male dominated medical paradigms. If cardiologists, physicians and general practitioners do not pay attention to women's symptoms or groups such as Maori that are most in need of prompt medical attention - nothing will change. The only way to reduce delays in seeking appropriate medical care for chest pain is to educate health professionals about women's level of risk for heart disease. Women participants' symptom experiences have shown that doctors dismiss uncommon symptoms such as fatigue and put it down to the stress of caring for adult children or spouses. General practitioners need to make the next step and relate these symptom experiences to evidence based guidelines where women's heart disease risk is linked to their burdens of caring or the social strain of family responsibilities. It was only when symptoms broke through efforts to conceal or relieve them that family or friends became part of the coping process.

*Recognising that women cope with pain using strategies to relieve menstrual or childbirth pain*

It is common sense that women participants would utilise familiar strategies from their lived experiences of symptoms. The link between menstrual and childbirth pain and enduring heart attack symptoms appears to be simple common sense. But health professionals have not made this link in previous studies. Women's roles have markedly changed and women's health services have primarily focused on health conditions that are solely for women such as breast or cervical cancer screening. Women's health services need to include heart disease risk factor screening, which is conducted with sensitivity to women and uses a women-centred approach. Health providers need to be educated about how the pressures of women's lives which emanate from the competing demands in the workplace combined with family responsibilities are placing women at more risk of heart disease than in the past.

*New approaches that acknowledge different language and patterns of behaviour are important for understanding symptom perceptions.*

Symptom descriptions provided the key to gaining more understanding into the way participants used plain language to describe their bodily sensations. The language provided clues about what the bodily sensations represented to each individual. From the individual participants' experiences of symptoms, differences in language and patterns of responses to symptoms emerged. Language differences in symptom

descriptions between women, men and Maori need to be recognised and acknowledged when people present for medical assistance. It was only when the symptom descriptions were linked to close scrutiny of the text that deeper meanings, which motivated participants' behaviour, surfaced in unexpected ways. New concepts were triggered for the researcher when she began to link throw-away comments from the text to the symptoms descriptions, for instance the reference to women's ability to bear the pain of childbirth or priding themselves on having more ability to bear pain than men. The reference to pain and scarring of cardiac, surgical procedures was also something that had never occurred to the researcher. Or the fact that women responded to painful symptoms using strategies that are commonplace for women, such as those activities used to relieve menstrual pain or dealt with pain using the childbirth angle. These discoveries pave the way for new attempts to reduce delay times.

*Acknowledging that a Maori strategy for coping with symptoms involves whanau*

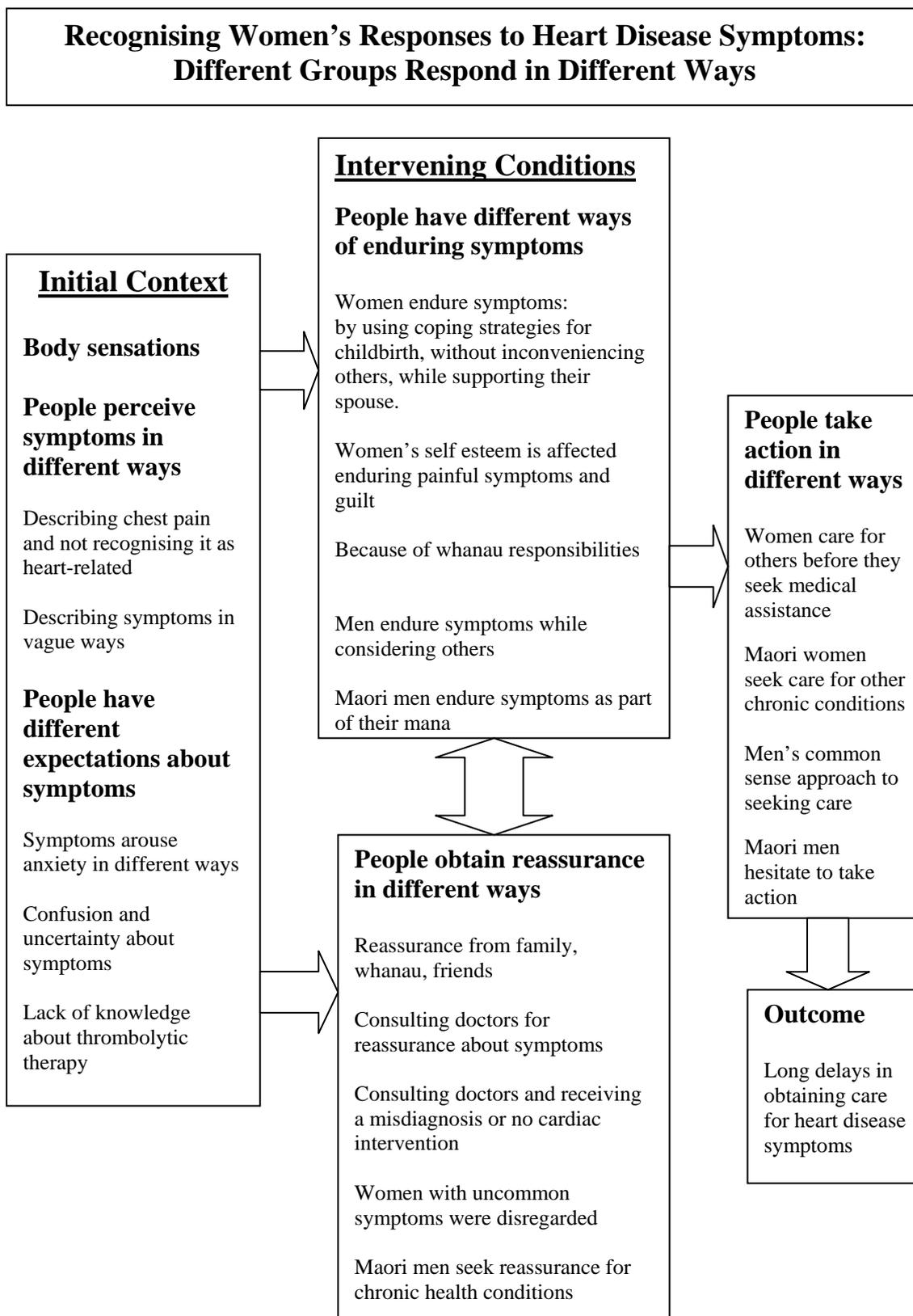
The findings show that Maori minimised their painful symptoms and were reluctant to discuss symptoms. This has been previously documented in other studies. Maori made decisions not to seek immediate medical assistance and obtained reassurance from whanau. These interactions were important to Maori. Maori endured distressing symptoms for lengthy periods because of whanau responsibilities. The role of whanau had a significant impact, as to whether, or not, the person suffering painful symptoms made a decision to get help or felt adequately supported to seek medical care.

*Personal crisis plans are required to promote new coping actions for heart symptoms*

Health providers need to take into account lay peoples' lived experiences of painful symptoms and how they have coped with them in the past. A platform of new coping strategies can be built by acknowledging what actions people take when dealing with symptoms of any kind. If a person has been identified as being at high risk or has angina, acute coronary syndrome or a heart attack, general practitioners can then establish and negotiate a crisis plan with their patients by discussing symptoms that might be expected and what actions to take. This new focus would change both doctors and their patients in terms of responsiveness to possible angina or heart attack symptoms. The participants' are experts in their own lives. They can learn new ways

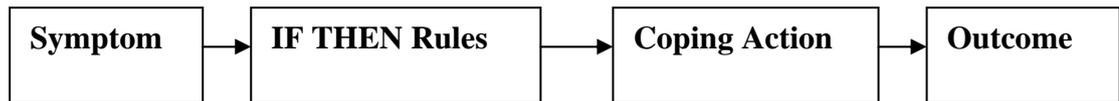
of coping with heart disease symptoms, if the doctors teach them how. Doctors need to re-think their biomedical approaches, which assume that lay people are unable to integrate knowledge about medical techniques such as thrombolytic therapy. It is common sense, if people knew what happened behind the closed doors of the hospital, if both women and men knew that there was a clot busting treatment - perhaps they would be motivated to get there faster.

**Figure 9.1: Model of response to heart disease symptoms**

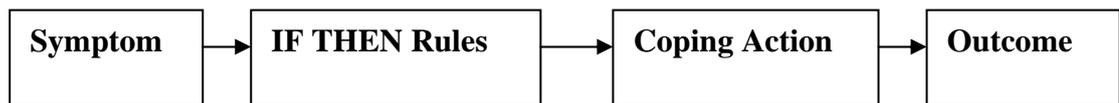


**Figure 9. 2: Self-regulatory components of symptom model**

**Self-Regulatory Model**



**Self-Regulatory Model with cognitive rules governing actions and relationships**



**RULES FOR RELATIONSHIPS AND CODES FOR SURVIVAL**

**Women have Codes of Endurance**  
**Men have Codes of Honour**  
**Maori women also have Codes of Tapu and Noa**  
**Maori men also have Codes of Tapu and Noa**

## **Discussion**

This is part four which covers the discussion of the two categories, 'people obtain reassurance in different ways' and 'people take action in different ways' that are previously reported in part one and part two of this chapter. The discussion of these categories covers some of the reasons why participants obtain reassurance for symptoms, the role of self treatment decisions, communication with doctors, participants perceptions of consulting a doctor, how age influences visits to a doctor and patient centred doctor interactions.

### **Obtaining reassurance**

Symptoms are experienced within the social context of each participant's surrounding environment. The majority of researchers have investigated symptom experiences that occur in individuals (R. Horne et al., 2000; H. Meischke et al., 2000; Perry et al., 2001). This means that the interactions with family members or the influence of significant others in the surrounding environment is often overlooked. Dracup and colleagues (1995) reviewed family dynamics or influence at the time of an AMI. They found that family members were the first to be consulted and this interaction led to lengthy delays. Conversely, when friends or work colleagues witness a cardiac event they may summon help promptly because they do not wish to be responsible for the illness. Dracup's review supported findings from the researcher's first study (Campbell, 1998) and this current research where discussion of symptoms with family members increased delay times.

For the majority of participants (except for those who had collapsed) the symptoms caused some internal distress, which is consistent with Mayou and associates' (2002) findings about levels of distress when presenting for chest pain symptoms at hospital. When symptoms became uncontrollable, confusing, affected physical activity and broke through participants' ability to alleviate them they sought comfort from people in their particular social environment which caused considerable delays. Confusion about the nature of symptoms compounded the delay problems because women participants' heart symptoms were more likely to be different. Few studies (Alonzo, 1986; Ruston, Clayton, & Calnan, 1998) have examined the impact of others who are present in the social setting where symptoms are experienced. Alonzo (1986)

describes the next phase as the lay evaluation phase where people sought lay or medical advice. He found that age and sex did not affect whether people transformed their illness from a personal experience to a social experience where others were informed. Ruston and colleagues (1998) qualitative study produced findings that were consistent with the participant data in that consulting lay others resulted in delays in comparing and discounting the experiences to rationalise the illness. These findings are consistent with other studies where the responses of family influenced care seeking at the time participants' were evaluating their symptom experiences. (Alonzo, 1986; Ashton, 1999; Dracup et al., 1995) Similarly, Pattenden and colleagues (2002, p. 1009) describe this phase as: "The presence of another person seemed to influence the decision making process". This study found that increase in pallor of patients was a signal to discuss the symptom and phone for help. Several spouses had reported that their partners were reluctant to make a fuss so the spouses made the decision to get help. These findings were similar to a report from one Maori woman participant who mentioned facial pallor as a symptom. As a result of painful symptoms, she lost colour in her face, her spouse saw this symptom as a signal to obtain help for her and being driven to the doctor. The trigger for socially acceptable action was that it was evident from the woman's pallor that she required medical help. These patterns of interactions are an additional factor that the researcher found which is not mentioned in the literature. There are rules about expected behaviour within social (Argyle & Henderson, 1985) relationships and the interactions surrounding care seeking. These rules determined that participants carried out the most socially acceptable action (discussed their symptoms with family) until the symptoms became so severe that emergency help was summoned.

For Maori, family involvement is crucial. The focus of Maori health models is that the individual is not viewed alone but part of a collective group that is called whanau (M. Durie, 1994). Communication with whanau members differs from Europeans in three ways. Firstly, Maori participants are part of wider family networks. Secondly, a state of optimal health and wellbeing for Maori depends on whanau support and thirdly, for Maori, minds and bodies are seen as inseparable. This perspective directly contrasts with westernised medical thinking that places emphasis on repairing the body and in a lot of cases ignoring state of mind. Medicalised treatment for heart disease has traditionally relegated psychological factors, a minor role in the disease

process. Hospital patients have complained that this narrow view of treatment has dehumanised them (Fisher, 1996). Whanau itself is viewed as a system where Maori people have a strong sense of belonging within the family group. Whanau are expected to care and share whanau members burden of illness (M. Durie, 1994).

A key finding from this research has shown that whanau interactions at the time of symptom onset are important indicators for care seeking behaviours. Indistinct references to symptoms and the interchanging language patterns such as naming the heart in Maori language *toku ngakau* (my heart) have been consistent throughout the Maori interviews. Language differences between European and Maori, such as these, show that cultural factors do impact on illness representations, because even the symptom terminology and naming of body parts was conveyed in a way that was culturally acceptable to Maori customs. Maori possess a different worldview than Europeans, through their unique knowledge of high death rates, which are held within the culture groups, which is consistent with scientific reports by Bullen (1997) and Durie (1994) in the literature. Also, there are different cultural ways (such as reciting a *karakia* or gifting the carved walking stick) of coping with symptoms, which are discussed in Durie's (2001) work.

Alternative views of cultural interpretations support that the acknowledgement of cultural behaviours is vital for understanding how cultural beliefs impact on illness representations. Ciofu Bauman (2003) has discussed this perspective. This author mentioned a study that shows that Chinese cultural views influence health behaviours (Kleinman et al., 1995). It is important to note that previous studies have barely touched on complex cultural interactions. Some researchers have discussed the work in terms of exotic cultural exceptions or cultures influenced by ancient symbolism. What these researchers do not emphasise is that the subject has barely been researched. As documented in Kay's (1993) work there is a systematic way of tracing the origin of beliefs about 'fallen fontanelle'. The researcher found that there had been no research tracing westernised and other cultural beliefs about the heart and linking these beliefs to illness representations. This is the reason the researcher has included not only lay people's beliefs, but also health professionals because both groups have grown up alongside this symbolic heritage. Ciofu Bauman (2003) states that cultures do not recognise affective distress. She is not addressing the

complexities of cultural constructions and the ways that symptom recognition can change within cultures as they are gradually exposed to new information. Farmer (1994) has provided support with the study examining how beliefs about the cause of AIDS changed over five years. To interpret Maori coping actions as lacking in affective distress, ignorant or irrational fails to acknowledge that cultural interpretations of illness representations are the key to designing more effective health education interventions that are gender and culture sensitive.

### **Self treatment**

Previous research has shown that decisions to try self-treatment, either over the counter remedies, home remedies, prescription medication, sublingual nitrates or by bed rest can result in prolonged delays (Campbell, 1998; McKinley, Moser, & Dracup, 2000; Perry et al., 2001; Ryan & Zerwic, 2003). The prehospital period is described as a time of intense coping, self-treatment activities such as resting, massaging the body or taking lay advice. Delay time can be decreased if family members or others usurp control and obtain medical care. Meischke and colleagues (1995) noted that self-treatment was the first coping strategy. The most frequently mentioned first thing that people did was resting, doing nothing or taking nitro lingual spray. Pattenden and colleagues (2002) reported that participants were using nitro lingual spray more times than recommended to treat chest pain. Attempts to relieve the pain resulted in confusion as to whether the pain represented angina or an AMI. Participants in this study carried out similar treatment activities such as resting, or doing nothing, which is consistent with previous research. Little is known about self-treatment activities because researchers have focused on sociodemographic and clinical characteristics and relate them to delay intervals. Leventhal and associates' (1992) research supports the findings from this study. Leventhal suggested that by examining people's behaviours or everyday procedures some light might be shed on the phenomenon of delay.

### **Communication with doctors**

Participants had lengthy delays as results of contacting their local doctors. Other researchers (Rawles & Haites, 1988) support this finding and documented prolonged time delays when people consult a doctor for heart symptoms instead of contacting emergency services. When people decide to get help, they may consult a doctor, dial

111 or travel directly to hospital. Many patients consult their medical practitioner as the first step and this results in prolonged delays (Alonzo, 1986; Leslie et al., 2000; Rawles & Haites, 1988; Wielgosz et al., 1988). Just as individual behaviour can produce a variety of responses to symptom experiences the medical response to presenting symptoms of ACS or an AMI can be variable. Doctors can vary widely in their training, knowledge, beliefs, attitudes and responsiveness (Alonzo, 1986).

People contact the medical practitioner's clinic or home to get an evaluation of their illness, to validate the need of emergency care or to find out where to obtain emergency assistance. Alonzo (1986) provides some support for the delays in this phase of receiving assistance which may be because the medical practitioner's advice dominates this phase, or because people wait in anticipation for medical advice. The majority of participants in Alonzo's study had contacted a medical practitioner, which resulted in considerable delays.

Later studies support these findings where there were longer delay times when patients contacted a doctor. Leslie and associates (2000) reported that delays of more than one hour were caused by lack of symptom recognition and more women contacted a doctor than men. Schoenberg and colleagues (2003) notes that existing literature shows that women visit their local doctors more than men. In this study, two categories impacted on women's reluctance to visit doctors for painful symptoms, problematic patient-physician interaction and structural barriers. This is described as a reluctance to visit the doctor even when confronted with extremely painful symptoms. The findings showed that women fear being viewed as "a worrier, hypochondriac or just ignorant", a case study showed that the physician had provided demeaning, biased medical care. When the participant had contacted the doctor by phone about symptoms she was told "You're too young to have a heart attack" and its probably indigestion and that if I lay off all that fried food, fried chicken, I'd be up and around real soon" (Schoenberg et al., 2003, p. 275). In the researcher's study, women participants had the same demeaning experiences. An example of this is where the doctor passed off one woman's fatigue as a symptom he had been told about many times but decided that it was not important to investigate it further. In contrast, one male participant who rarely visited the doctor was quietly matter of fact, when describing his symptoms and expected to get his symptoms attended to

promptly and to obtain treatment for angina. This man received prompt help from his doctor. Overall, women participant's experiences with their doctors showed that their symptoms were not recognised as heart related and they did not receive appropriate medical attention which is supported by the findings from Leslie (2000) and Schoenberg (2003).

### **Participant's perceptions about consulting a doctor**

When participants perceived that they were ill they sought reassurance and medical evaluation of their symptoms. Discrepancies between the doctor and the patient's views of illness can bring communication failures in any of the three stages of the self-regulatory model (Baumann, Cameron, Zimmerman, & Leventhal, 1989) (illness representation, coping or appraisal) and cause delays. Evidence from Baumann and associates (1989) supports the findings where medical practitioners talk focuses on representational attributes such as symptoms, nature of the disease and potential consequences. A Maori male participant sought help for asthma, as he felt comfortable with the familiar treatment procedures. His case shows how difficult it is for participants to describe the symptoms correctly in order to get the right treatment. Leventhal and colleagues (1997) support how difficult it is for patients to obtain the right information from their doctors. Doctors rarely provide information on coping strategies for illnesses such as heart attacks and virtually never inform patients about illness appraisal. Leventhal and colleagues found that patient's coping strategies for hypertension treatment were determined by their illness perceptions and episodic memories rather than beliefs held by the medical profession that the disease is asymptomatic.

### **Age influences visits to the doctor**

Most participants were older and retired. Several studies provided empirical support for older people perceiving that their symptoms were due to old age. Ottesen and associates (1996) found that large numbers of patients are already in contact with a doctor, for instance people who were older than 65 years and those patients with diabetes mellitus or angina. Keller and colleagues (1989) found that people classify illnesses as caused by ageing or not caused by ageing. If people attribute increased disease severity and decreased control of symptoms to advancing age this has major implications for coping strategies. Leventhal and associates (E. A. Leventhal &

Crouch, 1997; H. Leventhal et al., 1997; H. Leventhal et al., 1999) found that age moderates the self-regulation process and older people may be less willing to spend physical and emotional energy to consult a doctor. A woman participant in her late 70's, had consulted her doctor for symptoms of fatigue, which later turned out to be a heart attack, but she received little assistance. Conversely, a woman in her fifties perceived that her angina symptoms were a consequence of being older and did not seek medical help. Prolonged delays in consulting doctors may pose an increased risk for the health of older people because advanced age is associated with reductions in physical strength, pulmonary and cardiovascular capacity (Baumann et al., 1989). A study participant in his early seventies expected to visit the doctor for the severe symptoms for a cold but did not expect to be told that he may be having angina symptoms. In contrast, McKinlay and associates (1996) reported that older women and men were prescribed more drugs for chest pain that may reflect a medical perspective that older people are less able to modify their behaviour. Medical practitioners need to know more about the importance of illness perceptions, and recognise typical and atypical AMI symptom presentations in older women. It was socially acceptable for women participants to attend their General Practitioner if they felt unwell. Some women participants believed that their symptoms were caused by fatigue or old age rather than heart disease. Their societal roles were acted out according to their gendered experiences. Women are more used to attending their local doctor for mild symptoms because they are tuned into their menstrual cycles throughout their childbearing years (Kitzinger, 1985). The majority of women participant's were older and retired. Their symptom experiences were grounded in their unique knowledge from possessing ageing female bodies. Thus they did not relate their symptoms to heart disease, (a male problem) because they perceived the symptoms as part of the ageing process.

### **Patient centred interactions with doctors**

Doctors are in a similar situation to participants because they both have competing demands on their time. Complex patient problems and shrinking resources can result in doctors being overwhelmed by their patients' needs. The conventional patient–doctor interaction is based on a biomedical model where illnesses are diagnosed and treated medically with little recognition of the person being treated. The patient centred model (Stewart, 1995) changes from illness centred medicine to patient

centred medicine that takes into account the patient as a whole person. It included the biomedical model and goes beyond it to consider the patient as a person. This method explores both the disease and the illness and attempts to understand the person as a whole. During the consultation process the doctor attempts to find common ground to identify problems and set treatment goals whilst being realistic. By reaching mutually acceptable decisions about the treatment goals, patients are more likely to have satisfaction, adhere to treatment regimens and be motivated to achieve improved health status.

Numerous studies (Gibler et al., 2002; M. M. Ottesen, Dixen, Torp-Pedersen, & Kober, 2003; M. M. Ottesen et al., 1996) have shown that reasons for extended delays because of medical consultations include recommendations to use existing medication (e.g. angina spray), not diagnosing the symptoms as cardiac in nature, the patients not contacting the doctor immediately and inaccurate information provide by administration staff. Medical consultations are an integral part of coping procedures that people use when they experience heart attack symptoms. Doctors need to recognise heart attack symptoms in older women. Medical consultations require more research to gain further understanding about patients and practitioners' interactions and the reasons for delay.

## **Summary**

This chapter has reported the findings for the categories 'people obtain reassurance in different ways' and 'people take action in different ways'. The first section covered ways that women endure symptoms, including how women compensate for other people's needs by hiding their pain or waiting for symptoms to disappear. Secondly men's ways of enduring symptoms were identified by how they expected to get assistance from their family, but exercised consideration to those around them or assumed as in the case of Maori men, that was part of their role or mana within the whanau. The category covering seeking reassurance explained how important it was for participants to obtain reassurance about symptoms in their familiar surroundings and the various ways that people went about getting reassurance. Consultation with doctors was another major source of advice about symptoms. But the findings showed that doctors might not provide the reassurance that participants expected

because they disregard uncommon symptoms or misdiagnosed heart symptoms. Participants coping activities to relieve symptoms ranged from: self treatment, seeking treatment for other chronic medical conditions which confused the situation, getting others to contact medical help or taking an extraordinary length of time to sort out arrangement for other family members before calling emergency medical assistance. A discussion of the findings encompassed obtaining reassurance, self-treatment decisions, communication with doctors, participant's perceptions of doctors, how age influences visits to doctors and patient centred communications with doctors. In the next chapter the conclusion and recommendations that have merged from the data for health service providers and policy makers will be discussed with suggestions for further research within the complexities of providing public education programmes in a more targeted approach for women and ethnic minorities, such as Maori.

## CHAPTER X: IMPLICATIONS

*The eighth deadly sin is to 'rock the boat'.*

Sandra Coney, Journalist, feminist, campaigner for patient's rights (Orsman & Hurley, 1992)

*Feminism isn't about hating men or putting them down. It's about empowering women and celebrating their achievements.* Cathie Sheat (*Quotable New Zealand women*, 1994)

### Overview

This chapter has three parts. The chapter covers the implications, conclusions and recommendations relating to the findings that make up the concept: 'Recognising Women's Responses to Heart Disease Symptoms': Different groups respond in different ways. The first part covers the findings and elaborates on issues surrounding the participants' experiences. The second part discusses the study implications in terms of what is known in the literature, what areas require further attention from researchers together with a discussion of the study limitations. The third part, the conclusion, outlines recommendations for making a difference for women's heart disease in terms of changes in policy making and other social actions such as changes in the media portrayal of heart attacks, as well as placing a focus on research strategies sensitive to women.

### Introduction

This research began with an exploration of Maori and European people's recognition and understanding of premonitory and actual heart attack symptoms, particularly emphasising women's responses. The study explored why so many people delay seeking appropriate medical care. Thirty participants and three Maori informants were interviewed in two different settings. The concept is made up of distinct parts that addressed several areas in the care seeking process. Participants had different ways of coping with symptoms. They endured symptoms for long periods because it was more socially acceptable to not make demands on others in their immediate social environment. The mundane language used to describe symptoms directly influenced the perception of symptoms and what consequences were expected from these

symptoms. The ways people obtain reassurance for distressing symptoms are important influences on participants' actions to seek medical care. In essence, participants were very concerned about permissible and sanctioned actions related to their coping strategies for symptoms.

The researcher's intuitive process for analysing the findings was different from the accepted norms of mainstream research. The data analysis was carried out in a back to front way by using the findings from women and related it to what is already known about men and heart disease. The initial clues indicating the results came first from the women's interviews and the everyday language used to describe symptoms. The second important clues came from the fieldwork observations while the Maori investigator was conducting interviews. The third set of clues was the Maori protocol for *karakia* in the pre-interview stage, the reluctance on the part of Maori participants to discuss their symptoms, the whispering process on the audiotapes when symptoms were discussed, and the silences on the tapes. It is what the researcher learned from European and Maori women participants that drove the final theoretical model. It was a humbling experience and the researcher hopes that she has done justice to the collaboration with Maori colleagues and the priceless treasures in the study dialogue.

Thirty years since researchers have identified the phenomenon of 'patient delay' people today, still do not recognise that their symptoms are actually serious or heart related. The self-regulatory approach (H. Leventhal et al., 1997) that underpins symptom perceptions and coping strategies, serves as a framework for understanding participants' experiences. This model uses a feedback loop as its central construct that emphasises people's common sense beliefs and problem-solving activities to deal with health problems. The individual's beliefs and representations, based on their personal experiences when they appraise bodily symptoms, are the triggers for subsequent coping actions. Participants' experiences have shown that symptom perceptions differ according to gender and culture. Most women participants appraised their symptoms as not being serious threats to their health because their pain was not severe. It was only when the pain broke through their attempts to relieve it that they stopped resting or self-treatment activities and sought help. When they sought help, they did not perceive that their symptoms were heart related which was reflected in their symptom descriptions or vague symptoms.

## **Recognising women's risk for heart disease**

The first step in reducing women's heart attack risk is to recognise that women are at risk of heart disease just as much as men. There is a global health plan in place to build components into the existing health system that address the gaps in services for women. Improved heart health services for women would need to span population health initiatives (education, community development, and advocacy for women), primary care services (personal health services, diagnosis, treatment, rehabilitation and support), investigation services, (laboratories, radiology and surgical interventions), specialist care (specialist physicians, hospital care and surgical procedures) and home support services (nursing, home care and social services). The Victoria Declaration ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000, p. 16) identified four areas that have the greatest influence on reducing the risk of heart disease for both women and men. These are:

- health-promoting dietary habits;
- a tobacco-free lifestyle;
- regular physical activity; and
- a supportive psychosocial environment

In accordance with these health promotion goals it is necessary for the prevention and management services to undertake a comprehensive strategy to raise women's awareness of their risk of heart disease through public health measures such as population health promotion using information, education, community mobilisation and policy advocacy. Primary health care is the first point of contact for women and their families. General practitioners need to establish prevention, diagnosis, treatment, rehabilitation and support for women with heart disease.

Recent evidence based guidelines for women and heart disease (Mosca et al., 2004) have been developed in the absence of clinical trial data specifically for women. The techniques for identifying CVD risk have changed from a 'have' or 'have not' condition to the assessment of CVD risk along a continuum. The guidelines recommend the following lifestyle interventions for primary prevention

- Consistently encourage women not to smoke and avoid environmental tobacco
- Consistently encourage women to engage in moderate physical intensity activity, 30 minutes every day of the week (e.g. brisk walking)
- Consistently encourage healthy eating patterns
- Encourage women to undertake weight maintenance or reduction by balancing calorific intake and physical activity
- Treatment and prevention of depression
- High risk women need to include Omega 3 and folic acid in their diets

Although the guidelines are in place, what has not been accomplished in New Zealand, are comprehensive health promotion programmes that raise awareness of heart disease as a major issue for women. Health promotion programmes sensitive to the needs of women and Maori need to be established and be developed by women, for women. The PEOPLE system (Raeburn & Rootman, 1998) health promotion programme “means that communities assess their own priorities for action, within their own value systems, and set their own goals” (Herd & Raeburn, 2003, p. 73). This type of ‘women centred’ intervention would encourage the empowerment and participation of women to develop structures that effectively promote their heart health.

### **Symptom interpretations**

To promote women’s heart health it is important to consider previous qualitative studies that examined symptom interpretations. Burgess and colleagues (2001) central theme is labelled ‘interpretation of symptoms’ it is explained as: “problems identifying and labelling the initial symptom discovered as one might prove to be breast cancer” (Burgess et al., 2001, p. 968). Women participants did not realise that their symptoms were serious. The study found that women were hesitant about making a medical appointment, as they did not want to bother the doctor. Scherck (1997) used two categories for symptom interpretation ‘Attending vs ignoring’ which they described as “Are these physical sensations and signs worthy of attention or can they be safely disregarded?” and ‘Comparing signs and symptoms’ described as “Do these physical sensations and bodily signs match a known ailment or illness?” (Scherck, 1997, p. 269). This study concentrated on symptom interpretation and the

matching of bodily sensations to previous illness experiences. If participants' symptoms matched their concept of a heart attack medical attention was sought. While Ruston and associates (1998) investigated delays using the category: 'Strategies for dealing with symptoms' described as "Although most informants assigned an inappropriate diagnostic label to their symptoms at this stage, the strategy adopted for dealing with the symptoms delineated three groups" (Ruston et al., 1998, p. 1062). The study was confined to case histories to explain delay times, and perceptions of heart attacks. Similarly, Pattenden and colleagues (2002) used case histories to explain symptoms. 'Appraisal of symptoms' was described as "The appraisal of symptoms was a dynamic process throughout the decision making time. Identifying and labelling symptoms often posed problems, and many participants thought that their symptoms were not serious enough to be a heart attack" (Pattenden et al., 2002, p. 1006). Miller's analysis (2000) used this category: "Cues were signs, symptoms, or self risk appraisal. Decisions to discount or attend to cues was dependent on the nature, intensity, and specificity of the cue to cardiac disease as well as the woman's knowledge and symptom validation with others" (2000, p. 83). The above studies have all used symptom experiences as the key category for analysing data. These studies were limited to symptom interpretation, explaining things by case histories and measuring delay times and stopped short of finding the important interactions with other people. Miller (2000) has taken symptoms as cues then related to women's knowledge and obtaining reassurance from other people. Finally, Schoenberg and colleagues used "symptom uncertainty" as a category which is described as "lack of familiarity with the sensations that are typically associated with CHD" (Schoenberg et al., 2003, p. 7). Miller's research (2000) which included reassurance and Schoenberg and colleagues (2003) research were the two studies that most closely matched the researcher's findings.

### **Self-regulatory model**

The model (H. Leventhal et al., 1997) underpins explains how symptom perceptions elicit coping strategies. In the researcher's study, participants undertook some form of coping behaviour for distressing symptoms with the addition of the rules for relationships, when people make preferences about what actions they will take for symptoms. Evidence has shown that the self-regulatory process captures illness perceptions and coping actions that are mediated by "if then" rules and also this study

has revealed the presence of other rules surrounding decision-making. The model can be difficult to use because of their multivariate and transactional character (Baumann et al., 1989). Investigators must cope with measurement of multiple factors and concepts when designing a study, so investigators are forced to decide when variables are dependent or independent. Even though the model is not new there is little empirical evidence for comparison of the study data. Baumann and colleagues (1989) mentioned that here is a lack of standardised instruments, which seemed to be a barrier to utilising the self-regulatory model. A Meta analysis of research on illness representations provides support for the construct and discriminant validity of the self-regulatory process. This review found that there were “moderate-to-strong” (Hagger & Orbell, 2003, p. 181) relationships between illness cognitions, coping strategies and outcomes. These authors recommended that future research must include longitudinal designs to measure how coping behaviours mediate illness representations and further testing of the model with the role of symptom appraisals. Researchers have used the model to compare two ethnic groups: Tongan and European, taking an individual or egocentric approach, arguing that incorrect illness beliefs can be altered (Barnes, Moss-Morris, & Kaufusi, 2004). This study does not acknowledge the influence of important institutions within Tongan culture (extended family, the monarchy and the church). Critics of this individualistic approach have noted that questioning of culture should explore further into the roles that these social beliefs play within Tongan society (Blakely & Dew, 2004).

The self-regulatory model is based on symptom perceptions. As the cardiac literature has shown cardiac symptom protocols are founded on work carried out in the sixties (Rose, 1962). Researchers using the self-regulatory model have assumed that cardiac symptoms are the same for both women and men. Current trials are reviewing cardiac symptoms. Investigators conducting the WISE study are carrying out new diagnostic symptom protocols for women and men (Merz et al., 1999; Rose, 1962). There is a need to gather more information about symptom presentations for three reasons: little is known about women’s heart disease symptoms, women may present at hospital with uncommon cardiac symptoms, and both women and men may present with vague or ‘virus like’ symptoms. The researcher’s findings have revealed that there is much confusion and uncertainty about symptoms. Future self regulatory studies need

to take the uncertainty about symptoms into account and further testing is required (H. Leventhal et al., 1997).

### **Recognising women's symptoms**

This study differs from mainstream research through its focus on finding out more about symptoms by using women's experiences to drive the analysis. Too often researchers have repeated studies with large populations of men. The few existing studies on women have not paid much attention to their gynaecological experiences of symptoms and pain. Menstruation, contraception, breast problems, pregnancy and childbirth activities all have particular sets of symptoms (Kitzinger, 1985; Oakley, 1976). As women are familiar with these symptoms they resort to habitual ways of dealing with the symptoms. Women are likely to be ten years older than men when they present with heart symptoms (Roger & Gersh, 1997). Women's symptom experiences are compounded by the ageing process, they tend to have more chronic conditions like asthma or elevated blood pressure. The presence of medical conditions presents a complex situation, which makes it harder for women to have accurate symptom perceptions. Raising awareness of angina or heart attack symptoms in women must take into account their uniquely feminine pain experiences. It is time for the medical profession to stop focusing on women's failure to present at hospitals promptly for thrombolytic treatment. Instead a closer look at the reality of women's' lives and more intensive consultation with women is required before changes in treatment seeking will occur. As previously mentioned the CVD guidelines for women emphasise prompt assessment of acute coronary syndrome and acute myocardial infarction. The guidelines were developed from studies that included women and could be generalised to women, but there was little evidence for women older than 80 years or ethnic minorities (Mosca et al., 2004). The WISE clinical trial (Merz et al., 1999) is currently examining women's ischaemic syndromes. It will be some years before the trial results will be released. Further research examining the differences in symptom presentations between women and men is vital for increasing knowledge levels for women's heart disease. Future research in this area would provide evidence relevant to populations and sub groups of women in New Zealand, which in turn, would lead to the development of further evidence based guidelines for women.

## **Recognising women's unique coping strategies for painful symptoms**

It is important to recognise that women cope with the pain of cardiac symptoms using strategies normally carried out to relieve menstrual or childbirth pain. The Victoria Declaration ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000) sets out a plan for establishing heart health services that is conducted by women and is sensitive to women's unique needs. The finding that women cope with their heart disease symptoms using age-old techniques to manage the pain of menstrual symptoms or the pain of childbirth labour is a 'commonsense' observation. This finding has not been discussed in any other studies of 'patient delay' to the researcher's knowledge. Women are proactive about their health because they are tuned into their body rhythms. If women know about their risk of heart disease they will be proactive about reducing their heart disease risk factors, for example, increasing their exercise levels and adopting a low fat diet. It is only a small step in the chain to raise awareness about getting to hospital promptly if women experience any form of chest pain or discomfort. Links can be made between women's habitual coping strategies and education programmes to seek the appropriate care for heart disease symptoms. Building links between what women already know about their health and what they need to know about heart health would connect health messages to existing women's health services such as antenatal and postnatal clinics, breast and cervical cancer screening clinics.

Since ancient times women have been the health providers within the family or extended family. Once women receive the knowledge about their heart attack risk they will extend this awareness to their spouses, children and extended families. This would mean that men's awareness of heart attack symptoms would be raised as the findings show that they take help and support from their spouses when sick. An example of this strategy that works in present day medicine is the size of stents and catheters (Gorman, 2003). They used to come in one size to fit men's blood vessels, now they make smaller instruments because women's hearts tend to be smaller. So education programmes can move from one-size-fits-all to programmes and services specifically designed for women that are women friendly.

## **Doctors need to recognise women's heart symptoms**

Most participants consulted their local doctor about their symptoms, which extended the delay times. The role of general practitioners, their interactions with patients in the community and recognition of uncommon symptoms, requires much more attention by researchers. When doctors are presented with cardiac symptoms reported by patients in their consulting room they have a duty to diagnose the physical pathology of the symptom, rule out any organic processes causing the symptom and then to provide medical treatment. If the cardiac symptoms persist, doctors need to refer patients for investigative procedures. After these steps have been taken doctors need to seek psychological reasons to understand the patient and the problematic symptoms (Stewart, Brown, & McWhinney, 1989). This strategy is supported by Mayou and associates' (2002) recommendations where awareness of psychosocial variables would assist in both the assessment and management of cardiac or non-cardiac pain. New approaches that acknowledge different language and patterns of behaviour are important for understanding symptom perceptions. Although consultation with significant others has been evident in the literature, there has been no attention paid to ways of obtaining reassurance for symptoms. As the findings show women and men have different ways of carrying out the act of reassurance. Acknowledgement of the role of whanau should take priority in establishing education programmes for heart symptoms.

Acute coronary syndrome has been termed 'acute confusional state' H. White (personal communication, July 20, 2004). Certainly the symptoms of angina, acute coronary syndrome and acute myocardial infarction created confusion for both participants and doctors. Medical images of heart attacks have been shaped by men throughout civilisation to create stereotypical images of men who are prone to having heart attacks. It is widely accepted in society for a man to suffer a heart attack because of his work stress. By the same token it is less acceptable for a man to have a nervous breakdown due to work stress. On the other hand the traditional medical response for women who present with vague or intermittent pains is to 'calm them down' with tranquillisers or promptly refer them to a gynaecologist for 'women's problems'. As the origins of beliefs about heart have shown - women are excluded from the picture. This contributes to the confusion and misdiagnosis of women with

heart symptoms. It is time to put strategies in place to re-educate the medical profession and other health professionals, whether they are women or men, to recognise that women (like the study participants) present with heart disease symptoms.

A further implication is the role of media exposure, for both the general public, and the medical profession to 'virus like' illnesses. The symptom descriptions of participants show that people can become blasé about vague or intermittent symptoms. The majority of participants responded in a commonsense way, according to popular media messages about viruses, by resting and waiting for the symptoms to disappear. This kind of confusion implies that medical researchers need to investigate in much more depth both common and uncommon symptoms of heart disease before educating the public.

Another implication is that the participants did not know about thrombolytic therapy. It would seem commonsense that if people knew exactly what treatment was available they would make every attempt to obtain the treatment promptly. As any reality television programme will show you people's interest is gained by over exposure to the latest medical treatments, such as through plastic surgery makeovers. The wider public are not delayers, victims sufferers or prolonged delayers, as they are used to demanding the latest medical care by using the internet or learning about medical procedures through reality television. It is time to shed the medical mystique that surrounds thrombolytic therapy and get the information out to the public. The latest research on prehospital thrombolysis shows that it drastically cuts door to needle time. Surely with modern technology such as having thrombolytic therapy available in conjunction with defibrillators for cardiac arrest prehospital delays could be significantly reduced. Strategies such as these could address the problems with public perceptions of emergency services.

### **Recognising confusion about heart symptoms**

Participants' expectations about symptoms depended upon whether or not they recognised their symptoms as heart related. In the majority of cases participants did not expect that their symptoms might have serious consequences. Confusion reigned

when participants' symptom turned out to be not what they expected. Initially, both women and men participants were confused and uncertain about their symptoms. Confusion also arises from modern messages about viral illnesses. To provide information about heart disease, angina or heart attacks that is effective, health professionals need to acknowledge potential confusion about symptoms in health messages and construct messages that are sensitive to gender and cultural issues.

After a diagnosis of heart disease, it is important to acknowledge that ancient beliefs, whether they come from westernised egocentric or sociocentric cultures, such as Maori, do have a subtle influence on illness representations. Yes, the heart acts as a pump to supply life-giving blood to all parts of the body. But the heart is an organ with emotional and spiritual significance for both European and Maori. The historical significance of the heart is central to this research, as it shows how beliefs about the heart still affect us in contemporary society. It is not only the participants that have inherited these beliefs it is also the medical profession. Health professionals and researchers need to take these ancient beliefs into account, as they are a source of additional anxiety for people with heart disease. The heart represents the core of their emotional being and the source of their physical life. These two concepts are intertwined they are not separate entities as portrayed in the duality of mind and body by modern medicine. From the examples of women's interpretations of philosophy, mythology, historical events, literary texts and scientific recordings it can be seen that women perceive these things differently to men. Christine de Pisan's (1982) written observations about scientific matters and the place of women renders the misogynist practices against women quite transparent. Contemporary interpretations by women of the actions of women in medieval literature show that women cannot take for granted that men's writings are the one truth. Shifts in perspectives to present day interpretations of ancient forms of 'positivist truths' allow women researchers to take a different look at the traditional knowledge foundations of heart disease. When women re-evaluate the knowledge about heart disease in terms of what is important and relevant to them, the traditional parameters that have underpinned medical research and practice will shift positively to embrace women's needs.

### **Participants' expectations about symptoms**

Numerous studies (Campbell, 1998; Dracup et al., 1995; R. Horne et al., 2000; H. Meischke, Eisenberg, & Larsen, 1993; H. Meischke, Eisenberg et al., 1995; Perry et al., 2001; Schoenberg et al., 2003) have shown that people experiencing heart symptoms do not expect them to be serious, life threatening or a heart attack. Common perceptions about heart attacks rely on media images where people clutch their chest with acute pain, collapse and die (Campbell, 1998; R. Norris, 1999). This is the most common problem when it comes to getting the message across to the wider public because people do not know that heart attack symptoms can occur intermittently or cause mild discomfort in the prodromal stages of the illness (Bett et al., 1993).

The second problem is that participants and people in the community do not know about thrombolytic therapy and do not realise such a treatment exists and is available at the hospital. The information from participants showed that only one man with the recorded occupation of chief executive knew about clot busting drugs. This finding is consistent with Gibler and colleagues (2002) where people with higher education or professional occupations arrived at hospital earlier for treatment. Another study showed that when thrombolysis was administered more quickly when it was available in the community instead of at the hospital (Svensson et al., 2003).

A third problem occurs when there is confusion between both patient and doctor in identifying heart disease symptoms. The fourth problem is that women do not know about their risk of dying from heart disease (N. K. Wenger, 2002). Therefore more information is required about typical and atypical heart symptoms and common misconceptions about heart disease need to be changed.

### **Beliefs drive coping strategies**

It has been documented (Campbell, 1998; R. Horne et al., 2000; Hendrika Meischke, Eisenberg, Schaeffer, Larsen, & et al., 1994; H. Meischke, Ho et al., 1995) that if people expect symptoms to be heart related (e.g. severe, crushing chest pain) they quickly seek medical assistance. Conversely if people experience symptoms and attribute them to other causes (e.g. chest tightness may be attributed to indigestion or asthma) they may have prolonged delays in seeking medical care. Difficulty in

recognising heart related symptoms arises from commonly held beliefs about heart attacks. A common perception of heart attacks is that people experience severe pain in the chest, resulting in a collapse and death is the expected aftermath (H. Meischke et al., 1997; R. Norris, 1999; Raczynski et al., 1999). People do not expect to use emergency services when they relate to their symptoms as causing mild discomfort not severe pain. The 'if then' rules in the self-regulatory model (H. Leventhal et al., 1999) have been proved from empirical evidence that if what an individual believes has been the cause of symptoms, these beliefs directly influence coping behaviour. However within this cognitive model emotions also affect personal responses to bodily sensations. It is fairly simplistic to look at the problem of delays in care seeking and take what participants talk about at face value (H. Leventhal et al., 1999). The heart is the one organ in the body that is clothed in emotion and mystique and shrouded with rich meanings that are inherent in most cultures from the beginning of time (Ciofu Baumann, 2003; M. Durie, 1994; Garro, 1988; Kidd & Wix, 1996; Kleinman et al., 1995; Milgrom, 1985; R. Reichbart, 1981; R. H. Reichbart, 1983). It is important that when people's beliefs are part of a care seeking equation, to acknowledge that the interpretations of heart symptoms are filtered through the perceptions of health professionals and lay people. These beliefs run deeply through our heritage and nurses, general practitioners, cardiologists and cardiac surgeons are not immune from them. These beliefs impact on social interactions that surround the care seeking encounters in medical settings.

As a woman first, and emerging grounded theory researcher second, it was truly amazing, shocking and deeply disturbing to undertake the journey to find where our beliefs had originated and then to find next to nothing about women's hearts. To observe the entrenchment of misogyny which has rendered women's heart disease, a serious health problem, fairly invisible. Obviously nothing much has changed with women's place over the centuries. But we have a marvellous opportunity to change this dreary landscape if women and men work alongside each other to improve each other's heart health.

### **Confusion about heart attack images**

Most participants both men and women did not relate their mild or intermittent symptoms to the acute symptoms of a heart attack. Prodromal symptoms were dealt

with through visits to the GP where they may or may not receive an accurate diagnosis. Schoenberg and colleagues (2003) used the label symptom uncertainty to describe confusion. Their definition was “lack of familiarity with the sensations that are typically associated with CHD might lead them to delay in formal medical care treatment seeking” (Schoenberg et al., 2003, p. 275). Other studies (Dempsey et al., 1995; Ruston et al., 1998) had used similar labels but Schoenberg’s (2003) description was the closest match to this study.

Although the literature has pinpointed patient confusion about heart symptoms there has been little mention about the involvement of doctors who become confused. The confusion may arise out of communication problems with symptom descriptions, where doctors and their patients talk different languages. (For comparisons of symptoms descriptions see Tables 9.1 and 9.2. Two studies raised this issue (Schoenberg et al., 2003; Tod, Read, Lacey, & Abbott, 2001). It was described by Schoenberg and colleagues (2003) in the category: ‘Problematic patient-practitioner interaction’ and described as “many women in this study are reluctant to make a physician visit, even when confronted with extreme discomfort”. A study (Grant & Hawken, 2000) of communication skills courses for medical graduates showed that they did not value the skills at the time when they were taught. A number of graduates did not even remember what they were taught in these courses. Graduates perceived these skills to be more useful when they became practising doctors. A frequent criticism about the courses was that emerging doctors would have liked more training in breaking bad news or eliciting a sexual history. Such criticism points to underlying issues (Grant & Hawken, 2000). Without further training in establishing a patient centred therapeutic alliance with patients, doctors may have difficulty with the complex interactions required of them. Doctors need to have self-awareness, listening skills, a concept of power dynamics and some idea about the issues of transference or countertransference. Transference is an unconscious process, which occurs when unresolved personal issues trigger the doctor’s response to their patient (Stewart et al., 1989) or, problems can arise out of the stereotypical images where the European male is more readily perceived as a heart patient. Comparing symptom presentations with the man who had been widowed (and experiencing the stress of grief) and the woman who had high anxiety levels showed that the man expected to obtain prompt help for angina whereas the woman’s doctor fixed on her anxiety which overshadowed any

assessment of her cardiac status. This is supported by McKinlay's (1996) observations where an assertive woman had presented three times to hospital with classic signs of a heart attack and was sent home with ulcer medications. Grant and Hawken (2000) have listed the topics taught to medical undergraduates, in the first year of training, students are taught about stereotypes. There is no follow up training in this area in later years. It is not surprising then that doctors respond to patient stereotypes given the lack of emphasis in medical courses. Another perspective within this sphere is that patients make decisions about treatment that corresponds to their views of themselves and within their social context (Kelly-Powell, 1997). Primarily, the anxious woman participant would possess a socially constructed view of herself and her social role. It would be out of character for her to challenge the power behind the doctor's treatment decision because the legacy inherited from messages about women's nervous or hysterical behaviour. Secondly, her lack of knowledge that women are susceptible to heart disease would make it impossible for her to make an informed decision about treatment options. Thirdly, both doctor and patient would not know that a risk factor for women's heart disease is the social strain of women's roles (J. McKinlay, 1996; Orth-Gomer & Chesney, 1997; N. Wenger, 2002).

### **Confusing contemporary health threats**

We are socialised to the concepts of intangible 'virus like' infections through popular images in films or the television media. For instance many science fiction films create dramatic scenarios where viruses take over and are so mysterious that cures are not found. As previously mentioned unusual presentations for acute myocardial infarction can be missed because of limited coding of symptoms that have not changed since 1962 (Rose, 1962). When participants presented late with 'flu like' symptoms or what they expected was influenza they would base their treatment decision on recent health messages, which are geared to decrease antibiotic usage for viral illnesses. Baker's (1999) pathology study found that 12 patients with 'flu ' symptoms had actually died from an AMI. In this study three participants described 'flu like symptoms which later resulted in treatment for heart disease.

### **Public perceptions of emergency services**

Health professionals assume that the public will automatically use emergency medical services, but one reason for patient delay is under use of emergency care. Lumpkin and colleagues (1986) surveyed the use of emergency health facilities. Over half of the people surveyed (66.5%) knew centres existed but 85% of people believed that the centres were not appropriate for major emergencies. There was confusion about the hours centres were open and reluctance to use the emergency system. Meischke and associates (1994) evaluated a direct mail campaign with core messages covering symptom recognition, treatment options and emphasising prompt action. No significant differences were found between intervention and control groups. However the intervention group were more confident about recognising symptoms of an AMI in another person but all respondents felt they would be too embarrassed to dial 911 for chest pain. Study findings were limited and not generalisable because they related to the media campaign that preceded the mail intervention. Meischke and colleagues (1995) conducted a later study with an analysis based on the self-regulatory model. Few people called emergency services as their first action. The analysis revealed that being older, being with other people and believing it was a heart attack was related to more frequent utilisation of emergency services.

Public education campaigns have not been the subject of much discussion in New Zealand. Hay (1993) and Bett (1993) suggested that an Australian Heart Week message had reached a high proportion of people but the campaign had not reduced delay times. Hay pointed out that people at risk should be targeted for education and agreed with Bett and colleagues that knowledge alone does not result in behavioural change. This study described a media campaign based on dramatic scenarios where heart attack victims were rescued by helicopters. This study surveyed patient without involving campaign organisers so the evaluation was not aligned with the intervention objectives. Overall these studies (Bett et al., 1993; Lumpkin et al., 1986; H. Meischke, Eisenberg et al., 1995; Hendrika Meischke et al., 1994) demonstrate public reluctance to use emergency services. It is not clear whether lay people participated in or were consulted about, planning these education campaigns. If debate does not encompass people's perceptions about illnesses that occur in daily life how can people relate their domestic health crises with vague, mild or intermittent heart attack symptoms to scenarios where people are being rescued by helicopters?

## **Recognising Maori perspectives**

When the researcher received the information from the Maori interviews she felt overwhelmed by what, we as Europeans do not know about Maori. European researchers are unable to gauge the depths of our own ignorance. Even though these bodies of knowledge were personal points of view, it reinforced for the researcher that investigators would need to acknowledge the unique contributions of other gendered or cultural groups that have different worldviews. Research initiatives to tackle serious health problems for other ethnic groups such as Maori need to be conducted and directed by Maori. In this way mainstream researchers would be saved from making assumptions about what constitutes Maori health knowledge. For it is a vast and as yet virtually untapped treasure house of resources that can be harnessed and tapped into, so that Maori can define heart health or heart attack messages that are sensitive to their needs.

The Kaumatua commenced his instruction by relating the way that Maori lived before colonisation of Aotearoa (New Zealand). He wanted to show the researcher the importance of dietary considerations in building a healthy population that was free from contemporary health problems such as heart disease. His superb oratory would leave people in no doubt that Europeans had much to learn from traditional Maori health strategies. For it is only in more recent times that clinicians in the cardiac field have linked the wellbeing of hearts, minds and communities together (Allan & Scheidt, 1996; Raeburn & Rootman, 1998). The story is a building block towards healthier communities for both Maori and European. It is only when we uncover this vital information that has remained hidden from us and rightly so; that we are going to form true partnerships in heart health. Maori had prolonged delays in receiving the appropriate medical attention because they minimised the seriousness of their symptoms and consulted with whanau for reassurance and support. Thus, acknowledging that a Maori strategy for coping with symptoms involves whanau discussion. The role of whanau should take priority in establishing coping strategies or crisis plans for heart disease symptoms.

## **New approaches to education programmes**

If delays in care seeking for heart disease symptoms are to be reduced, new education approaches need to be sensitive to women's issues. Global researchers have coined the term women's "double workload" ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000, p. 19) where women have primary responsibility as family caregivers and participate in the paid work force, which is not only an additional risk factor for heart disease but also a factor in delays to seek medical treatment. Women's "double workload" is related to the drastic role changes for women, such as active participation in the workforce, while continuing to be the main provider of care for family members. It is only when these circumstances are acknowledged in education methods, that key heart health messages, will be taken on board by women. New education programmes related to treatment delays for Maori, need to take into account lack of access to medical as a result of poverty, Maori reluctance to discuss their symptoms and Maori women's significant responsibilities for whanau members.

## **Strengths and limitations of the study**

The research was conducted in a number of field sites with participants from the acute AMI in the hospital setting and from hard to reach populations in the community by using general practitioner's clinics and Maori health trusts (Creswell, 1998; Mays & Pope, 1995). The study obtained information from the participant's perspectives instead of relying on hackneyed research methods where researchers assumptions guided the actual data collected. The choice of gathering data from general practitioners' clinics allowed the researcher to observe events throughout a wider cycle, where participants sought care for angina, and in some cases suffered an acute myocardial infarction with subsequent surgical interventions such as an angioplasty or heart surgery. There was wide consultation and collaboration with other researchers and Maori to develop the study that led to a more effective way of gathering rich data that was meaningful for Maori and useful in a practical sense for dissemination amongst Maori. Maori interview schedules and the Maori language were more acceptable for Maori participants, which made it easier to recruit participants. Instead of just tape recoding the questions in the Maori language the interviewer used traditional Maori protocol in conjunction with the language (for example a karakia

was held before the interview) to conduct the interviews. The match of women researcher and interviewer to women participants made it easier to talk about their experiences, anger and dissatisfaction with men general practitioners and cardiologists. This made the whole point of research worthwhile because the aim was to get a closer look at the daily world of women with heart disease. The interviews in hospital contrasted with the clinic interviews to provide a cycle of coping strategies at the time of an acute event and allowed patterns of behaviour in the community to be assessed over time.

The trustworthiness of the findings were tested in five ways (Charmaz, 1990; Creswell, 1998; Mays & Pope, 1995; Thomas, 2003). Two independent coders conducted a consistency check on the clarity of categories. Other practices to ensure reliability of the qualitative data both in content and structure were carried out by supervisors and the Maori advisors. Ensuring that the sample included examples from the text that supported or were different from the emerging theory tested links between categories. Consultation with stakeholders was carried out and participants were sent their transcript to review and correct so they became an integral part of the research process. The field data was compared with the literature to test qualitative conclusions. Delay times for arrival at hospital were compared with medical records to ascertain accuracy. The researcher as the research instrument, has endeavoured to describe the research process simply and clearly so that participants' behaviour illustrates how differences in symptom perceptions give rise to preferences for particular coping strategies.

A significant problem is that the researcher had to rely on participants' memories. The onset of angina or chest pain is a stressful event and a person's memory may be affected by their unique experience and therefore is subject to recall bias or inaccurate recall of the event. Self-reports from the participants might be coloured with their own point of view or selective recall of events. The research design did not encompass interviews with family members or bystanders. The researcher could be biased in choosing the particular locations and collection of sample. Perhaps different locations may have produced a different data set. The research data consisted of stories about participants' experiences with heart disease. This could be looked at as an assembly of personal stories and impressions (Mays & Pope, 1995) but the

findings are consistent with empirical evidence relating to the phenomenon. The study lacks generalisability in two ways. First the study was not designed to be statistically significant, so the findings cannot be generalised to other populations. Secondly, the findings are derived from particular populations in terms of using GP clinics and Maori Health Trusts that are only located in the Auckland region. The study could be reproduced using the same interview schedule and the same or similar locations. However, different researchers may or may not come to the same conclusion by using exactly the same grounded theory method.

## **Conclusion**

This research has been a tiny step in recognising that participants carry out commonsense survival strategies to deal with distressing heart symptoms. They cope with their symptoms in a vacuum, without knowledge of the essential medical procedures that are vital if death from heart attacks is to be prevented. If the medical profession paused for a nanosecond from their daily interventions they may consider that it is sensible to share their knowledge. Closer consultation with communities would empower people to take control of their mortality from heart disease not only with lifestyle changes but also establishing emergency heart attack care. In this way, cardiac care would be accessible in the local community instead of hidden behind the hospital doors. European and Maori women shared their uncertainty and confusion about their heart symptoms. In the review of the literature, writing and research for this study it is the first time in the researchers knowledge that heart beliefs and delay behaviours for acute myocardial infarction have been systematically linked from the origins of ancient heart beliefs. Another important finding was that women participants coped with their cardiac pain using strategies used for menstruation and childbirth. The literature review has shown how centuries of misogynist behaviour has contributed to the invisibility of women with heart disease and a lack of scientific research for women and heart diseases. Recognition of the way our beliefs have been handed down through the ages is the key to forming new interpretations of women's responses to heart disease and making positive changes to the way cardiovascular research prevention and management strategies are carried out to ensure women's heart health is optimised.

## **Recommendations**

### **Prevention and management strategies for women and heart disease**

In order to establish a comprehensive population health strategy for women and heart disease the government must take more action to improve this health condition. Population health interventions need to include a wide range of population health techniques such as gathering more information with epidemiological studies, plan programmes for women's heart health promotion, initiate research studies to address the additional risk factors for women as they continue to be family caregivers and have demanding roles in the workplace. Provide community education about heart disease risk factors and heart attack action specifically for women. A submission by the researcher was included in the New Zealand Health Strategy using resources from the Victoria Declaration ("The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action," 2000) to specifically address the prevention and management of heart disease for New Zealand Women. The core values underpinning policy initiatives are:

- To ensure that women's heart health is a fundamental right
- To achieve optimum heart health women must have equity in health
- To achieve active participation by women at policy making levels
- To be have solidarity of action between women and men in establishing global, national and community policies for women and heart disease

The primary goal for raising awareness that heart disease is the No 1 killer for women was developed by the Advisory Board and conference attendees for the First International Conference on Women Heart Disease and Stroke. The study findings have shown that women participants lacked information about their risk of heart disease and the manifestation of cardiac disease with painful symptoms accompanying acute coronary syndromes or myocardial infarctions. The findings are the basis for instituting larger research programmes that investigate women's cardiac symptoms. Any concerted action needs to consider seriously that the first important step in raising awareness for women, their families and the clinicians responsible for their medical care is:

Recognition that heart disease is a major health problem for women.

This statement not only sets the scene for public health action and raising awareness for women and heart disease it also renders visible this major risk to women's health. The following recommendations outline steps in making a difference to women's heart health:

### **Recognising women's risk for heart disease**

Traditionally women's health has focused on childbearing and reproductive issues, such as services exclusive to women: breast cancer, cervical cancer and menopause. Until recently, the assessment of women's heart health has received little attention from scientific communities. The active involvement of women in identifying and improving the key determinants for heart health is an important international and national priority. A primary aim would be to assess the sustainability of lifestyle changes, which is a key factor if there are to be improvements in women's cardiovascular health status. Drastic changes in women's societal roles have increased their risk for heart disease. Empirical evidence shows that women are subject to many competing demands that make them reluctant to consider their own heart health needs. The promotion and prevention of heart disease among women can only be accomplished with attention to the realities of women's various roles within the family, the community, the workplace and the country. Women's 'double burden' of caring for families and actively participating in the workplace has recently been identified as an additional heart disease risk factor for women. Achieving optimal cardiovascular health for women is severely impaired by socio-economic determinants such as poverty, education, culture, access to health services and the unequal position and power of women. All of these factors shape women's views about themselves and their perceptions about cardiovascular disease. It is by understanding what the barriers are and building capacity to overcome these barriers that sustainable lifestyle changes for women can be achieved. The following recommendations are the basis for health promotion in women's heart health:

- A1. To ensure that New Zealand government health agencies, scientific and research communities, community and voluntary agencies adopt proactive policies and invest resources in policies and programmes that improve women's heart health.

A2. To coordinate resources in the prevention and management of heart diseases among women in New Zealand.

A3. To ensure that women take leadership roles and actively participate in policy formulation and development of a strategic direction for women's heart health outcomes.

A4. To establish a National Advisory Committee for Women and Heart Disease.

1. To develop infrastructures at national regional and community levels that institute mechanisms, which ensure women are consulted to involve them directly in policy formulation.
2. To achieve improved heart health for women, both men and women need to be working together to establish a strategic direction for future services.
3. To provide resources to assist communities in documenting and evaluating services and activities for women's heart health.
4. To develop heart health promotion programmes that address older women's needs as they live longer and are more likely to experience disability from chronic heart disease.
5. To develop alternative ideas for heart health promotion programmes generated by women and ethnic minority groups.
6. To maximise the benefit gained by conducting interventions to raise women's awareness about their risk of heart disease, health promotion programmes would need to:
  - Target programmes more specifically to women's unique heart health needs as outlined in the recent American Heart Association evidence based guidelines for cardiovascular disease prevention in women.

- Include psychosocial measures designed for women as recommended by the new guidelines and the recent clinical trials such as the WISE study evaluations.
- Conduct independent evaluations (on a modest scale) to assess medical staff and women's perceptions of the lifestyle change process.

### **Recognising women's symptoms of acute coronary syndrome or AMI**

Lack of awareness about heart health issues that are specific to women has impeded progress in research initiatives. Medical research, epidemiological studies, many drug therapy protocols and medical interventions administered to women are based on research that has been conducted with male populations. There has been little investigation or adjustment for gender differences. A recent review of information on women and heart disease between 1957 and 2000 showed that there was little information specific to women and heart disease until the 1980's. An article in the 1960's focused on strategies for women to take care of their husband's hearts, which deflected attention from women's heart disease. Empirical evidence shows that there are gender stereotypes for heart disease. Women believe that they are more likely to die of breast cancer than heart disease. Research initiatives need to move away from interventions that perpetuate gender stereotypes in order to create effective women's heart research programmes. The creation of new research programmes for women that optimised medical endpoints and proved cost effectiveness must address gender differences in heart disease. The new programmes need to consider underlying beliefs surrounding gender stereotypes as well as psychological and social issues if any randomised trial intervention is to be efficacious. The following recommendations would provide a foundation for further exploration of women's heart symptoms.

- B1. To fund research programmes on cardiovascular health, therapeutic interventions and secondary prevention among women.

- B2. To provide appropriate education training and supportive environments for women researchers.
- B3. To involve women directly in the identification of women's research issues, methods and analyses and interpretation of results.
- B4. To conduct further research specifically addressing a range of issues for women and heart disease as little is known from women themselves or about women's physiological or psychological manifestations of heart symptoms.
- B5. To conduct ongoing surveillance of women's health outcomes, monitor and evaluate health services and community supports using gender sensitive indicators to obtain information for programme planning and which demonstrates accountability to the population for the allocation of resources.
- B6. To compile a database of information, and disseminate research surveillance monitoring and evaluation findings to policy makers and service providers.
- B7. To ensure that governments and other health funding agencies develop mechanisms to incorporate the findings of successful pilot projects into the mainstream health system.
- B8. To conduct research programmes which include a triangulation of data using both qualitative and quantitative methodologies to produce statistically significant evidence accompanied by rich descriptive data to expand the knowledge base.

### **Recognising confusion about heart attack symptoms**

The media image of the typical male heart attack victim held by lay people influences women and men's beliefs about heart disease. Women, their family members and friends, hold commonsense models of heart disease with male images and, in turn, these images influence any care seeking activities. To obtain new community based solutions to an age-old problem with the National Heart Foundation of New Zealand community representatives, without relying solely on the perceptions and efforts of

health professionals. New education programmes need to be tailored specifically for older people, especially older women, Maori and other ethnic minorities. The following recommendations form a strategy for new public heart attack education:

- C1. To develop heart attack action programmes that portray less melodramatic images of heart attacks as represented by popular media culture.
- C2. To develop medical education programmes which acknowledge differences in symptom presentations for acute coronary syndrome or AMI and coping strategies specifically relating to women, Maori and whanau members.
- C3. To collaborate with the media industry to change current presentation of stereotypical roles and to increase awareness of the reality of women's lives and their social responsibilities.
- C4. To conduct a consultation process, using government, health providers and community representatives to obtain women's views and Maori perspectives about how to design more effective heart attack messages.
- C5. To consult and collaborate more closely with Maori to learn more about their cultural illness perceptions with whanau members and meld together this knowledge in a more meaningful way that is more culturally acceptable in order to improve Maori mortality rates from heart attacks.

## **APPENDIX A: Hospital Study Interview Schedule**

### **HOSPITAL STUDY**

#### ***RESPONSE TO SYMPTOMS OF YOUR HEART ATTACK INTERVIEW SCHEDULE***

**Principal Investigator: Cheryl Campbell** (PhD student)

Department of Community Health  
Faculty of Medicine & Health Science  
The University of Auckland, Private Bag 92019,  
Auckland.  
Phone: 3737599 extn 6749

**Supervisors: Associate-Professor John Raeburn,  
Professor Colin Mantell**

To.....

#### **Invitation to Participants for the Response to symptoms of your heart disease study.**

You are invited to take part in this study about your response to the symptoms of your heart disease. Your decision to take part in this study is your free choice and if you decide not to take part your future health care will not be affected. The time that you will have to consider your decision is approximately seven days from your clinic appointment date.

#### **Information about the Study**

Heart disease is the leading cause of death in New Zealand and recent studies show that most deaths happen within 1 hour of the first symptoms. There is a hospital treatment available called thrombolytic therapy. If this treatment is given soon enough it can limit the amount of damage to the heart, when a person has a heart

attack. Approximately, 50% of people that have heart attacks die before reaching hospital, because, when their symptoms start, they delay seeking medical care.

We are doing a study to see if we can find out more about the way that people respond and what happens when they get the first signs and symptoms of heart disease. For this study, we will select people who have angina, a high risk of having a heart attack and those people who have been admitted, for the first time to the Coronary Care Unit after having a heart attack. The study will be conducted over a three-year period. Participants will be asked to answer a questionnaire after they have been approached by their General Practitioners or Practice Nurses. People who wish to participate in the study can contact the researchers who will explain the questionnaire, and go through it with you. The interview takes approximately 50 minutes. The researchers would prefer to audiotape the interview, but this would only be done with your consent and the tape could be turned off at any time, or you can withdraw information. If you do wish to be interviewed please complete the attached consent form. Any information that you provide in an interview will be confidential and your name will not be used. The confidential information will be kept by Cheryl Campbell (Principal Researcher) at the Department of Community Health.

### **Study Benefits**

This study will provide important information to help determine the reasons that people delay seeking medical care for symptoms that lead to a heart attack. It will help us understand what specific information is needed about heart attacks, by people in the community so that they will know when to go straight to hospital. It will not cost any money to take part in answering the questions on this interview schedule.

### **Participation**

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you will receive the standard treatment or care available, and this will not affect any future care or treatment.

If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your future health care.

## **General**

After the study is completed the information on the interview schedules will be transcribed and held at the Department of Community Health. A copy of the transcribed interview will be sent to you. If you have any further questions regarding this study or would like to know more about it please feel free to contact Cheryl Campbell on the phone number listed on the front. If you need an interpreter, one can be provided. You do not have to answer all the questions, and you may stop the interview at any time.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate,

Name of Advocate: \_\_\_\_\_

Telephone: \_\_\_\_\_

## **Confidentiality**

The information provided by you, and the results of the questionnaire will be available only to the researchers undertaking the study. This information will be treated with strict confidentiality. No material that could personally identify you will be used in any reports on this study.

## **Results**

There will be a delay time between the time of your interview and the publication of the results. However, if you have any queries about the results please contact Cheryl Campbell - Telephone: 3737599 extension 6749. Participants are able to get the published results of this research from the Department of Community Health.

**Thank you very much for your time and help in making this study possible.**

## **Statement of approval**

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

**Please feel free to contact the Principal Researcher- Cheryl Campbell - Telephone: 3737599 extension 6749 if you have any questions about this study.**

## ***INTERVIEW SCHEDULE***

INFORMATION FROM CLINICAL NOTES

Onset of symptoms

Time of arrival at hospital

The following questions are about your experience of having a heart attack. We would like to find out exactly what happened when you had your heart attack.

1) *Could you tell me if you had any symptoms in the days leading up to your heart attack?*

2) *Could you tell me when these symptoms first started?*

Length of time before the onset of symptoms relating to the heart attack episode

3) *Could you please describe your experience from the time you first noticed your symptoms?*

4) *What did you think had caused these symptoms at the time?*

5) *What was the 'first thing' that you did when you noticed the symptoms?*

6) *What did you do to relieve your symptoms?*

7) *Did you talk to anyone about your symptoms?*

8) *Have you ever been told by a doctor that you had angina?*

9) *What time did you first notice the symptoms of your heart attack?  
(If pre-infarct angina then add "for the symptoms which resulted in you having a heart attack)*

10) *When were your symptoms at their worst?*

11) *I'd like to find out exactly what symptoms you had as part of your heart attack. Could you describe these symptoms for me?*

12) *On a scale of 0 to 10 (if 0 is no pain and 10 is pain as bad as you can imagine) how would you rate the severity of the pain (or discomfort if no pain) when it was at its worst?*

- 13) *Where were you when the symptoms first started (the symptoms leading up to when you came into hospital)?*
- 14) *Who else was present when the symptoms first started (the hours leading up to when you came into hospital)?*
- 15) *What did you think it was when the symptoms first started (the symptoms you had the hours leading up to coming into hospital)?*
- 16) *Have you suffered from (Whatever label was used) before coming to hospital?*
- 17) *Could you tell me why you believed it was (Labelled condition)?*
- 18) *Did you take any medicines when the symptoms first started?*
- 19) *Did you think at any time before calling for help that you might be having a heart attack ? (or it was heart related)*
- 20) *Could you explain why you did not think it was a heart attack?*
- 21) *Approximately, how long from the first onset of symptoms (that brought you into hospital) did it take to cross your mind that it might be a heart attack?*

Write time in hours and minutes \_\_\_\_\_

- 22) *What was the main reason why you first thought that it might be a heart attack or heart-related?*
- 23) *Was there anything in particular that made you feel that it wasn't a heart attack at this stage?*
- 24) *What was the main reason why you decided to get help?*
- 25) *What was the 'first thing' that you did?*
- 26) *Could you tell me what time it was when got help?*  
 .....  
 (Registration time at A&E.....from notes)
- 27) *Who made the decision to get help?*

- 28) *Who actually got the help?*
- 29) *What sort of help did you get?*
- 30) *How did you get to hospital?*
- 31) *Was there anything in particular that stopped you calling for help or going to hospital earlier?*
- 32) *If I had stopped you in the street before you had this heart attack and asked you what you thought the symptoms of a heart attack would be like. What would you have said?*
- 33) *So, would you say that your heart attack was....?*
- 34) *Before you had this heart attack what would you have said were your chances of having a heart attack?*
- 35) *Could you tell me how severe do you think was your heart attack? (Not necessarily what the doctors have said to you)*
- 36) *What did you think your risk of having a heart attack was?*
- 37) *How easy is it for you now to accept that you have had a heart attack?*
- 38) *Do you know of any medicine that makes a heart attack smaller?*
- 39) *Is there anything else that you would like to add?*

## **APPENDIX B: Community Study Interview Schedule**

### **COMMUNITY STUDY**

#### ***RESPONSE TO YOUR SYMPTOMS OF ANGINA OR HEART DISEASE INTERVIEW SCHEDULE***

**Principal Investigator: Cheryl Campbell** (PhD student)

Department of Community Health  
Faculty of Medicine & Health Science  
The University of Auckland, Private Bag 92019,  
Auckland.  
Phone: 3737599 extn 6749

**Supervisors: Associate-Professor John Raeburn,  
Professor Colin Mantell**

To.....

#### **Invitation to Participants for the Response to symptoms of your heart disease study.**

You are invited to take part in this study about your response to the symptoms of your heart disease. Your decision to take part in this study is your free choice and if you decide not to take part your future health care will not be affected. The time that you will have to consider your decision is approximately seven days from your clinic appointment date.

#### **Information about the Study**

Heart disease is the leading cause of death in New Zealand and recent studies show that most deaths happen within 1 hour of the first symptoms. There is a hospital treatment available called thrombolytic therapy. If this treatment is given soon enough it can limit the amount of damage to the heart, when a person has a heart

attack. Approximately, 50% of people that have heart attacks die before reaching hospital, because, when their symptoms start, they delay seeking medical care.

We are doing a study to see if we can find out more about the way that people respond and what happens when they get the first signs and symptoms of heart disease. For this study, we will select people who have angina, a high risk of having a heart attack and those people who have been admitted, for the first time to the Coronary Care Unit after having a heart attack. The study will be conducted over a three-year period. Participants will be asked to answer a questionnaire after they have been approached by their General Practitioners or Practice Nurses. People who wish to participate in the study can contact the researchers who will explain the questionnaire, and go through it with you. The interview takes approximately 50 minutes. The researchers would prefer to audiotape the interview, but this would only be done with your consent and the tape could be turned off at any time, or you can withdraw information. If you do wish to be interviewed please complete the attached consent form. Any information that you provide in an interview will be confidential and your name will not be used. The confidential information will be kept by Cheryl Campbell (Principal Researcher) at the Department of Community Health.

### **Study Benefits**

This study will provide important information to help determine the reasons that people delay seeking medical care for symptoms that lead to a heart attack. It will help us understand what specific information is needed about heart attacks, by people in the community so that they will know when to go straight to hospital. It will not cost any money to take part in answering this questionnaire.

### **Participation**

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you will receive the standard treatment /care available, and this will not affect any future care or treatment.

If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your future health care.

### **General**

After the study is completed the information on the questionnaires will be transcribed and held at the Department of Community Health. A copy of the transcribed interview

will be sent to you. If you have any further questions regarding this study or would like to know more about it please feel free to contact Cheryl Campbell on the phone number listed on the front. If you need an interpreter, one can be provided. You do not have to answer all the questions, and you may stop the interview at any time.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate,

Name of Advocate: \_\_\_\_\_

Telephone: \_\_\_\_\_

### **Confidentiality**

The information provided by you, and the results of the questionnaire will be available only to the researchers undertaking the study. This information will be treated with strict confidentiality. No material that could personally identify you will be used in any reports on this study.

### **Results**

There will be a delay time between the time of your interview and the publication of the results. However, if you have any queries about the results please contact Cheryl Campbell - Telephone: 3737599 extension 6749. Participants are able to get the published results of this research from the Department of Community Health.

**Thank you very much for your time and help in making this study possible.**

### **Statement of approval**

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

**Please feel free to contact the Principal Researcher- Cheryl Campbell - Telephone: 3737599 extension 6749 if you have any questions about this study.**

## ***INTERVIEW SCHEDULE***

### **INFORMATION FROM CLINICAL NOTES**

#### **Date and time of clinic appointment**

We would like to find out about your experience with symptoms of angina or heart disease. The following questions will ask you about your symptoms and how you dealt with them.

1) *Could you tell me if you had any symptoms in the days leading up to your clinic appointment?*

2) *Could you tell me when these symptoms first started?*

Length of time from onset of symptoms leading up to the clinic appointment.

3) *Could you please describe what happened from the first time you first noticed the symptoms?*

4) *What did you think had caused these symptoms at the time?*

5) *What was the 'first thing' that you did when you noticed the symptoms?*

6) *What did you do next?*

7) *Have you ever been told by a doctor that you had angina?*

8) *What time did you first notice the symptoms that resulted in you making a clinic appointment?*

9) *When were your symptoms at their worst?*

10) *Could you describe your symptoms for me?*

11) *On a scale of 0 to 10 (if 0 is no pain and 10 is pain as bad as you can imagine) how would you rate the severity of the pain (or discomfort if no pain) when it was at its worst?*

12) *Where were you when the symptoms started?*

13) *Who else was with you when you were experiencing these symptoms?*

14) *What did you think was going on when the symptoms first started (the symptoms leading up to your clinic appointment)? Did you think it was angina? If not, how did you label it to yourself?*

- 15) *Have you suffered from (Whatever label was used) before coming to the clinic?*
- 16) *Could you tell me why you believed it was (Labelled condition)?*
- 17) *Did you do anything to relieve your symptoms when they started?*
- 18) *If at the time you thought your symptoms were not heart-related, had you changed your mind by the time of making your clinic appointment?*
- 19) *If you did not pick up they were heart symptoms why did you think you didn't?*
- 20) *What was the main reason why you decided to get help?*
- 21) *What was the 'first thing' that you did?*
- 22) *Could you tell me how long it was after your symptoms started that you contacted the clinic for an appointment?*
- 23) *Who made the decision to contact the clinic?*
- 24) *How did you get to clinic?*
- 25) *Did anything stop you from going to the clinic earlier?*
- 26) *Could you tell me how you felt about going to the clinic?*
- 27) *Could you tell me a bit more about your experience at the clinic?*
- 28) *Before you had these symptoms what did you think symptoms of angina (or heart disease) would be like?*
- 29) *So, would you say that your angina or heart disease symptoms are?*
- 30) *Before you had angina (or heart disease) what would you have said your chances of having heart disease?*
- 31) *Could you tell me how severe do you think your angina (or heart disease) is?*
- 32) *How easy is it for you now to accept that you have angina or heart disease?*

33) *Do you know of any medication that will stop a heart attack or make the heart attack smaller?*

34) *Is there anything else you would like to tell me about your angina (or heart disease)?*

## APPENDIX C: Hospital Study Invitation

### HOSPITAL STUDY

## INFORMATION SHEET

### INVITATION TO PARTICIPATE IN THE RESPONSE TO SYMPTOMS OF YOUR HEART ATTACK STUDY

**Title:** Response to symptoms of your heart attack study

**Principal Investigator:** Cheryl Campbell (PhD. student)

Department of Community Health  
Faculty of Medicine & Health Science  
The University of Auckland, Private Bag 92019,  
Auckland.

Phone: 3737599 extn 6749

**Supervisors:** Associate-Professor John Raeburn,  
Professor Colin Mantell

To.....

#### **Invitation to Participants for the Response to symptoms of your heart attack study.**

You are invited to take part in this study about your response to the symptoms of a heart attack. Your decision to take part in this study is your free choice and if you decide not to take part your future health care will not be affected. The time that you will have to consider your decision is one day from your admission date.

## **Information about the Study**

Heart disease is the leading cause of death in New Zealand and recent studies show that most deaths happen within 1 hour of the first symptoms. There is a hospital treatment available called thrombolytic therapy. If this treatment is given soon enough it can limit the amount of damage to the heart, when a person has a heart attack. Approximately, 50% of people that have heart attacks die before reaching hospital, because, when their symptoms start, they delay seeking medical care.

We are doing a study to see if we can find out more about the way that people respond and what happens when they get the first signs of a heart attack. For this study, we will select approximately 40 people who have angina, a high risk of having a heart attack and those people who have been admitted, for the first time to the Coronary Care Unit after having a heart attack. The study will be conducted over a three-year period. Participants will be asked to answer questions on from an interview schedule when they are well enough to be transferred to a medical ward.

**The researchers will review your medical records to gather information for this study.** The researchers will explain the interview schedule, and go through it with you, which takes approximately 50 minutes. The researchers would prefer to audiotape the interview, but this would only be done with your consent and the tape could be turned off at any time, or you can withdraw information. If you do wish to be interviewed please complete the attached consent form. Any information that you provide in an interview will be confidential and your name will not be used. The confidential information will be kept by Cheryl Campbell (Principal Researcher) at the Department of Community Health.

c.campbell version 2 / 19.7.2000

## **Study Benefits**

This study will provide important information to help determine the reasons that people delay seeking medical care for symptoms that lead to a heart attack. It will help us understand what specific information is needed about heart attacks, by people in the community so that they will know when to go straight to hospital. It will not cost any money to take part in answering this questionnaire.

## **Participation**

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you will receive the standard treatment or care available, and this will not affect any future care or treatment.

If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your future health care.

## **Compensation**

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation within its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this study.

## **General**

After the study is completed the information on the interview schedules will be transcribed and held at the Department of Community Health. A copy of the transcribed interview will be sent to you. If you have any further questions regarding this study or would like to know more about it please feel free to contact Cheryl Campbell on the phone number listed on the front. If you need an interpreter, one can be provided. You do not have to answer all the questions, and you may stop the interview at any time.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate,  
Name: Health Advocates Trust Northland to Franklin: Telephone: 0800 205 555

c.campbell version 2 / 19.7.2000

## **Confidentiality**

The information provided by you, and the results of the questionnaire will be available only to the researchers and the supervisors undertaking the study. This information will be treated with strict confidentiality. No material that could personally identify you will be used in any reports on this study.

## **Results**

There will be a delay time between the time of your interview and the publication of the results. However, if you have any queries about the results please contact Cheryl

Campbell - Telephone: 3737599 extension 6749. Participants are able to get the published results of this research from the Department of Community Health.

**Thank you very much for your time and help in making this study possible.**

**Statement of approval**

This study has received ethical approval from the Auckland Ethics Committee.

**Please feel free to contact the Principal Researcher- Cheryl Campbell - Telephone: 3737599 extension 6749 if you have any questions about this study.**

<sup>1</sup> c.campbell version 2 information sheet 19.7.2000

## APPENDIX D: Community Study Invitation

### COMMUNITY STUDY

## INFORMATION SHEET

### INVITATION TO PARTICIPATE IN THE RESPONSE TO YOUR SYMPTOMS OF YOUR ANGINA OR HEART DISEASE STUDY

**Title:** Response to symptoms of your heart disease study

**Principal Investigator:** Cheryl Campbell (PhD student)

Department of Community Health  
Faculty of Medicine & Health Science  
The University of Auckland, Private Bag 92019,  
Auckland.  
Phone: 3737599 extn 6749

**Supervisors:** Associate-Professor John Raeburn,  
Professor Colin Mantell

To.....

**Invitation to Participants for the Response to symptoms of your heart disease study.**

You are invited to take part in this study about your response to the symptoms of your angina or heart disease. Your decision to take part in this study is your free

choice and if you decide not to take part your future health care will not be affected. The time that you will have to consider your decision is approximately seven days from your clinic appointment date.

### **Information about the Study**

Heart disease is the leading cause of death in New Zealand and recent studies show that most deaths happen within 1 hour of the first symptoms. There is a hospital treatment available called thrombolytic therapy. If this treatment is given soon enough it can limit the amount of damage to the heart, when a person has a heart attack. Approximately, 50% of people that have heart attacks die before reaching hospital, because, when their symptoms start, they delay seeking medical care.

We are doing a study to see if we can find out more about the way that people respond and what happens when they get the first signs and symptoms of angina or heart disease. For this study, we will select approximately 40 people presenting for an appointment at a General Practitioner's clinic, who have angina, a high risk of having a heart attack and those people who have been admitted, for the first time to the Coronary Care Unit after having a heart attack. The study will be conducted over a three-year period. Participants will be asked to answer questions from an interview schedule after they have been approached by their General Practitioners or Practice Nurses. People who wish to participate in the study can contact the researchers who will explain the interview schedule, and go through it with you.

**The researchers will review your medical records to gather information for this study.** The interview takes approximately 50 minutes. The researchers would prefer to audiotape the interview, but this would only be done with your consent and the tape could be turned off at any time, or you can withdraw information. If you do wish to be interviewed please complete the attached consent form. Any information that you provide in an interview will be confidential and your name will not be used. The confidential information will be kept by Cheryl Campbell (Principal Researcher) at the Department of Community Health.

c.campbell version 2 / 19.7.2000

### **Study Benefits**

This study will provide important information to help determine the reasons that people delay seeking medical care for angina or heart disease symptoms that lead to a heart attack. It will help us understand what specific information is needed about

heart attacks, by people in the community so that they will know when to go straight to hospital. It will not cost any money to take part in answering this questionnaire.

### **Participation**

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you will receive the standard treatment or care available, and this will not affect any future care or treatment.

If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your future health care.

### **Compensation**

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation within its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this study.

### **General**

If you need an interpreter one will be provided. After the study is completed the information on the interview schedules will be transcribed and held at the Department of Community Health. A copy of the transcribed interview will be sent to you. If you have any further questions regarding this study or would like to know more about it please feel free to contact Cheryl Campbell on the phone number listed on the front. If you need an interpreter, one can be provided. You do not have to answer all the questions, and you may stop the interview at any time.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate,  
Name: Health Advocates Trust Northland to Franklin: Telephone: 0800 205 555

c.campbell version 2 / 19.7.2000

### **Confidentiality**

The information provided by you, and the results of the interview schedule will be available only to the researchers and the study supervisors undertaking the study. This information will be treated with strict confidentiality. No material that could personally identify you will be used in any reports on this study.

**Results**

There will be a delay time between the time of your interview and the publication of the results. However, if you have any queries about the results please contact Cheryl Campbell - Telephone: 3737599 extension 6749. Participants are able to get the published results of this research from the Department of Community Health.

**Thank you very much for your time and help in making this study possible.**

**Statement of approval**

This study has received ethical approval from the Auckland Ethics Committee.

**Please feel free to contact the Principal Researcher- Cheryl Campbell - Telephone: 3737599 extension 6749 if you have any questions about this study.**

c.campbell version 2/ 19.7.2000

## APPENDIX E: Hospital Study Consent Form

### HOSPITAL STUDY

## CONSENT FORM

### RESPONSE TO THE SYMPTOMS OF YOUR HEART ATTACK STUDY

#### CONSENT FORM - Participant to complete

**Title of Project:** Response to your symptoms of heart disease study.

**Principal Investigator:** Cheryl Campbell

(under the supervision of Associate-Professor John Raeburn and Professor Colin Mantell)

**Name of**

**Participant:** \_\_\_\_\_

English	I wish to have an interpreter	Yes	No
Maori	E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau	Ae	Kao
Samoaan	Oute mana' o e iai se fa' amatala upu	loe	Leai
Tongan	'Oku fiema'u ha fakatonulea	lo	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Nuiean	Fia manako au ke fakaaoga e tagata fakahokohoko vagahau	E	Nakai

I have read and understood the information sheet dated \_\_\_\_\_ for volunteers taking part in the study designed to find out reasons for patient delay in seeking treatment for chest pain. I understand that taking part in this study is voluntary (my choice) and that I may withdraw at any time, and this will in no way affect my future health care. I have had an opportunity to ask questions and have them answered. I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study. I have had time to consider whether to take part. I know who to contact if I have any questions about the study.

I understand that the researchers will review my medical records to gather information for this study. I understand that I will need to be interviewed with a "Response to the symptoms of your heart attack" questionnaire.

I consent to my interview being audio-taped.

I wish to receive a copy of the results, or;

I would like the researcher to discuss the outcomes of the study with me.

I \_\_\_\_\_ (full name) hereby consent to take part in this research; Date: \_\_\_\_\_

Signed: \_\_\_\_\_ Participant

Name of Witness: \_\_\_\_\_

Signature of Witness: \_\_\_\_\_

Full Names of Researchers:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

c.campbell/ version 2 19.7.00

If you have any concerns about this study you may contact the Principal Investigator, **Cheryl Campbell - Telephone: 3737599 Extension 6749** at the Department of Community Health- University of Auckland

Health Advocates Trust

Phone: 0800 205 555

c.campbell/ version 2 / 19.7.2000

## APPENDIX F: Community Study Consent Form

### COMMUNITY STUDY

### CONSENT FORM

## RESPONSE TO YOUR SYMPTOMS OF ANGINA OR HEART DISEASE STUDY

### CONSENT FORM - Participant to complete

**Title of Project:** Response to your symptoms of heart disease study.

**Principal Investigator:** Cheryl Campbell

(under the supervision of Associate-Professor John Raeburn and Professor Colin Mantell)

**Name of**

**Participant:** \_\_\_\_\_

English	I wish to have an interpreter	Yes	No
Maori	E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau	Ae	Kao
Samoaan	Oute mana' o e iai se fa' amatala upu	loe	Leai
Tongan	'Oku fiema'u ha fakatonulea	lo	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Nuiean	Fia manako au ke fakaaoga e tagata fakahokohoko vagahau	E	Nakai

I have read and understood the information sheet dated \_\_\_\_\_ for volunteers taking part in the study designed to find out reasons for patient delay in seeking treatment for chest pain. I understand that taking part in this study is voluntary (my choice) and that I may withdraw at any time, and this will in no way affect my future health care. I have had an opportunity to ask questions and have them answered. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study. I have had time to consider whether to take part. I know who to contact if I have any questions about the study.

I understand that the researchers will review my medical records to gather information for this study. I understand that I will need to be interviewed with a "Response to the symptoms of your angina or heart disease" questionnaire.

I consent to my interview being audio-taped.

I wish to receive a copy of the results, or;

I would like the researcher to discuss the outcomes of the study with me.

I understand that my General Practitioner (GP) will be informed of my participation in this study.

I \_\_\_\_\_(full name) hereby consent to take part in this research; Date:\_\_\_\_\_

Signed:\_\_\_\_\_Participant

Name of Witness:\_\_\_\_\_

Signature of Witness: \_\_\_\_\_

Full Names of Researchers:

\_\_\_\_\_

---

---

If you have any concerns about this study you may contact the Principal Investigator, **Cheryl Campbell - Telephone: 3737599 Extension 6749** at the Department of Community Health- University of Auckland Health Advocates Trust  
Phone 0800205555

c.campbell / /version 2/ 19.7.2000

## APPENDIX G: Maori Invitation

### He Rangahau i te Iwi Whanui

#### He Panui

He powhiri tenei kia uru mai kite urupare mai ki nga tohu mate o te manawa me te ngakau.

Kaupapa: He urupare ki nga tohu o nga mate o to ngakau, hei tirohanga

Aporei Whakawa: Cheryl Campbell (Taura PhD)

#### **Te Tari o te Hauora Iwi Whanui**

Waahanga o te Rongoa me te Hauora Puutaiao

Te Whare Waananga o Tamaki Makaurau

Pouaka Motuhake 92019

Tamaki Makaurau.

Waea 3737599 waea iti 6749

Nga Kaitirohanga:

Ahorangi: Colin Mantell

Ahorangi-Whakahoa: John Raeburn

Kia .....

**He tono tenei kia uru mai koe ki tenei rangahau, e paana ki o whakautu ki nga tohu o te mate ngakau**

He tono tenei kia uru mai koe ki tenei rangahau, mo nga whakautu ki nga tohu o te mate ngakau me te hemanawa.

Kei a koe ano to tikanga ina uru mai koe ki tenei whakaaturanga, engari ena whakaaro koe ki te whakataha mai e kore tenei e arai atu i te tiaki a te Hauora i a koe.

Te wa hei whakaaroaro mou kia uru mai ki tenei rangahau, e whitu ra, mai i to whakaritenga i te whare hauora.

#### **Nga korero mo tenei Rangahau**

I roto o Aotearoa nei, ai ki nga rangahau hou, e matemate ana te nuinga o nga tangata i te mate ngakau i roto i te haora tuatahi o te tohu o te mate nei.

Kei te hohipere he ahua hei whakaora i te mate, ko te ingoa he ‘ whakaoranga rehu ohotata’. (thrombolic therapy)

I te wa e pamai ana te mate ngakau, ina kakama te mahi i tenei ahuatanga ka iti ake te patu i te ngakau o te tangata.

E tata atu ki te rima-tekau pae heneti o nga tangata kua mate i te ngakau whakaete i mua i te taengatu ki te hohipere, no te mea, i te putanga o nga tohu o te mate nei ka nui te whakaroa ka tae ki nga kai tangotango o te hohipere.

E mahi nei matou i tenei whakaaturanga, kia mohio ai matou i te ahua o te whakautu o ia tangata, i te putanga tuatahi o nga tohu, a nga taru mauui o te ngakau. A mo tenei whakaaturanga ka whiriwhiria e matou, kia tata atu ki te tahi mano e wha rau tangata, e mauui ana te manawa, e oho rere ana te ngakau whakaeke, me nga tangata taimaha te mauui o nga ngakau, i muri mai o te whakaekenga ki te whare o te hauora o te takuta..

### **E whakaae ana au kia tirohia ano aku whakaaturanga o te hauora, hei kohinga korero mo tenei rangahau.**

Ka tirohia tenei rangahau i roto o nga tau e toru. Ka inoingia nga tangata i whiriwhiria mo tenei whakaaturanga kia whakautungia nga patai rarangi a te kaipatapatai, i muri mai i te tutakitanga ki to ratou Takuta-a- Iwi me te neehi a rohe. Te hunga e hiahia ana ki te uru atu ki roto o tenei rangahau, me whakamohio atu ki nga kairangahau, kia whakamarama atu i nga ture o te kaupapa patapatai ki te hunga hiahia. E rima tekau meneti noiho te wa mo te patapatai. Ko te wawata a nga kairangahau me nga kai whakahaere te patapatai nei i runga o nga mihini tango korero, engari i runga o to korero whakae, ka whakakorea te tango korero i runga o te mihini ena hiahia koe, me te mukua o nga korero o runga o te mihini. Mehemea koe e hiahia ana kia patapataia koe, whakakitia mai te pepa patapatai, nga korero e tuku na mai e koe ki au, ahakoa ko to ingoa, kanui te tapu – kia : Cheryl Campbell, te Aporei Whakawa, i te Tari o te Hauora Iwi Whanui.

### **Nga Whakaaturanga Hua**

He take tino nui tenei, e kokohi nei matou i eenei whakamaramatanga hei awhina i te rapu i te take e whakaroa nei te tangata ki te rapu neehi, takuta mo te hunga e mauui tia ana te ngakau. A mo nga taru mauui o te ngakau whakaeke. Ma enei tirohunga, me nga matauranga, ka mohio tatou ki te tari i nga turoro tika tonu ki te hohipere. Ko te mea nui o eenei patai, kahore he utu mo te whakaki enei patai.

## **Te Urungatanga**

I to urunga mai ki roto i tenei whakahaerenga ko koe ano to rangatira, mena koe kahore e hiahia ana ki te uru atu ki te whakaaturanga, me te noho wahanga, e pai ana, e kore e poroa to tikanga tiaki o te hauora.

E na whakae koe kite uru atu, e kore e araitia koe ki te puta mai i taua huihuinga. E ahei ana koe ki te puta mai i te wa e hiahia ana koe, e kore e pa te kapua nga wa kei te haeremai me to tiaki e te hauora.

## **Kapeneihana**

Ina whara noiho koe i te waa kua uru mai koe ki tenei rangahau, ka tiakina koe i raro i nga ture whakaiti a te Kapeneihana mo nga Aituaa. Mena he patai au e paana ki te ACC, me e tahi atu ahuatanga whiua mai ki te kairangahau nei, maana ano hoki e whakautu, i mua i to whakaaenga ki te urumai ki tenei rangahau.

## **Tirohanga Whanui**

Ki te hiahia koe kia whakamaoritia nga korero nei, ma matou e whakarite tena. A te mutunga o tenei whakaaturanga, ka tuhia nga korero katou mai i nga ripene hopu korero, ka pupuritia enei tuhinga i te Tari o Hauora Whanui. Ka tonouatu ki a koe he whakaahua o enei tuhinga korero. Mena he patai au mo tenei whakaaturanga, whakaatu mai ki ahau: Cheryl Campbell i runga i taku waea. Kei a koe ano to tikanga ina kore koe e hiahia ki te whakautu nga patai katoa, a ka hiahia koe ki te whakamutu nga uiuinga, kei a koe tou ano mana.

Ina whai paatai koe e awangawanga ranei, e paana ki to mana tangata i a koe kua uru atu ki tenei rangahau, me whakaatu atu koe ki Nga kaitautoko i nga kaupapa o te Hauora me te Hauaa.

Ingoa o te Kaitautoko.....

Waea .....

## **Nga korero tapu**

Nga korero i tukua mai e koe, me nga hua o nga uiuitanga katoa, ka pupuritia e nga kairangahau me nga kaitirohunga i roto i tenei rangahau anake hei titiro. Ko enei korero he tapu ki te tangata kee. E kore koe ake e mohiotia i nga whai korero i roto i E korerawa koe e mohiotia i roto i nga tuhinga o tenei rangahau.

## **Whakaotinga**

Ka takaroa te waa I muri mai o te uiuinga me te panuitanga o nga tuhituhinga. Mena he patai au e paana ki nga tuhunga nei whakaatu mai kia Cheryl Campbell – Waea 3737599 waea iti 6749. Mo koutou i uru mai ki tenei rangahau, haeremai ki te Tari o Te Iwi Whanui ki te tiki mai i nga te panuitanga o nga uiuitanga ma koutou..

**Tena koutou katoa e awhina mai i tenei kaupapai.**

## **Purongo Whakaetanga**

Kua whakae mai te Te Poari o te Mana Tangata o te Hauora mo te Rohe o te Raki ki tenei rangahau.

**Ka hiahia koe ki te korero mo tenei rangahau, whakaatu mai ki ahau Cheryl Campbell – Waea 3737599 waea iti 6749.**

c.campbell/iritana hankins/information sheet version 2 / 19.7.2000

## APPENDIX H: Maori Consent Form

### He Tirohunga Hohipere

#### Pepa Whakaae

Te whakautu mo nga ki nga tohu o te mate manawa.

Pepa whakaae – Ma te kaiwhakauru e whakaoti.

Te ingoa o te Kaupapa: Te rangahau o o whakautu ki nga tohu o te mate manawa

Aporei: Cheryl Campbell

(I raro i nga tirohunga a te Ahorangi a Colin Mantell me te Ahorangi /whakahoa a John Raeburn.)

Te Ingoa o te tangata whai painga: .....

Maori	E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau	Ae	Kao
-------	--	----	-----

*Kua kite au i nga korero i runga i te pepa o te ra --- a e matau ana ki te kaupapa mo era e uru mai ana ki te rangahau, kia kitea ai e aha te take o te hunga e pangia ana e tenei mate, e takaroa nei i mua o te haerenga kia tirohia o ratou mate uma.*

**E marama ana au, kei ahau taku tikanga ki te uru atu ki tenei rangahau , a me te whakarere nooki, a e kore enei mahi whakararuraru i te awhina a te hauora i ahau i nga ra kei te heke mai.**



## APPENDIX I: Lists Of Themes From Qualitative Studies

### List 1: 1995-2000

LIST 1: Author	Method	Themes
Dempsey et al, (1995) N=16 (women)	Structured open ended questions to study psychosocial process in care seeking for a heart attack Grounded Theory	<ul style="list-style-type: none"> <li>• Maintaining and relinquishing control</li> <li>• Symptom awareness</li> <li>• Perceived threat</li> <li>• Perceived insignificance</li> <li>• Self treatment</li> <li>• Lay consultation</li> </ul>
Scherck, (1997) n=30 (6 women and 26 men)	Open ended interview to study recognising a heart attack Constant comparative	<ul style="list-style-type: none"> <li>• Attending vs Ignoring signs and symptoms</li> <li>• Comparing signs and symptoms</li> </ul>
Ruston et al, (1998) n=43 patients and 21 other people present	Semi structured interviews to study action during a cardiac event Constant comparative	<ul style="list-style-type: none"> <li>• Strategies for dealing with symptoms (Non delayers, Delayers, Extended delayers)</li> <li>• Perception of risk and heart attacks before the event</li> </ul>
Wiles, (1998) n=25 (12 women and 13 men)	Semi structured interviews at two points in time to study heart attack perceptions Grounded theory	<ul style="list-style-type: none"> <li>• Lose trust in “official” accounts of cause and recovery</li> <li>• Questioned explanatory power of official accounts</li> </ul>
Mc Sweeny and Crane, (2000) n=40	Interviews to study symptoms experienced prior to a heart attack Content analysis Constant comparison	<ul style="list-style-type: none"> <li>• Prodromal symptoms</li> <li>• Most frequent prodromal symptoms</li> <li>• Most frequent acute symptoms</li> </ul>
Miller, (2000) n=12 (women) 3 Nurses, 1 Cardiologist	Interviews to study Cues for help seeking for cardiac symptoms Grounded Theory	<ul style="list-style-type: none"> <li>• Cue apprehension</li> <li>• Cue assimilation</li> <li>• Medical consultation</li> </ul>

## List 2: 2001-2003

<b>LIST 2:Author</b>	<b>Method</b>	<b>Themes</b>
Burgess et al, (2001) n=46 (women)	Semi structured interviews to study delays reporting breast cancer symptoms Framework method	<ul style="list-style-type: none"> <li>• Interpretation of symptoms</li> <li>• Attitudes to general practitioner attendance</li> <li>• Beliefs about the consequences of medical help seeking</li> <li>• Perception of competing priorities</li> <li>• Triggers to action</li> </ul>
Tod et al, (2001) n=14, 9 primary care staff 1 Physicians group 5 Community groups	Semi structured interviews Group interviews	<ul style="list-style-type: none"> <li>• Structural, personal, social, cultural</li> <li>• Past experience and expectations</li> <li>• Diagnostic confusion, knowledge and awareness</li> </ul>
Pattenden et al, (2002) n= 22 (2 women and 20 men) 11 (10 spouses and 1 son)	Semi structured interviews to study decision making for heart attacks Constant comparative	<ul style="list-style-type: none"> <li>• Appraisal of symptoms</li> <li>• Perceived risk</li> <li>• Previous experience</li> <li>• Psychological and emotional factors</li> <li>• Use of the NHS</li> <li>• Context of the event</li> </ul>
Schoenberg et al, (2003) n= 40 (women)	Semi structured interview and 3 focus groups to study women's perceptions of cardiac symptoms Grounded Theory	<ul style="list-style-type: none"> <li>• Symptom uncertainty</li> <li>• Problematic patient-physician interaction</li> <li>• Competing social demands</li> <li>• Structural barriers to treatment seeking</li> </ul>

## APPENDIX K: Profile Of Participants

**This table outlines the sex, age and occupation of European participants**

<b>Sex</b>	<b>Age</b>	<b>Occupation</b>
Female	57 years	Clerk
Female	58 years	Company Director
Female	71 years	Retired
Female	73 years	Retired
Female	75 years	Retired
Female	75 years	Retired
Female	76 years	Retired
Female	78 years	Retired
Female	79 years	Retired
Male	46 years	Mechanic
Male	48 years	Manager
Male	62 years	Technician
Male	64 years	Chief Executive
Male	66 years	Caretaker
Male	69 years	Model
Male	73 years	Retired
Male	80 years	Retired
Male	83 years	Retired

**This table outlines the sex, age and occupation of Maori participants**

<b>Sex</b>	<b>Age</b>	<b>Occupation</b>
Female	45 years	Factory worker
Female	64 years	Sickness Beneficiary
Female	66 years	Retired
Female	68 years	Retired
Female	72 years	Retired
Male	46 years	Labourer
Male	52 years	Self Employed
Male	54 years	Invalid Beneficiary
Male	54 years	Labourer
Male	57 years	Unemployed
Male	61 years	Sickness Beneficiary
Male	68 years	Retired

## APPENDIX L: Data Collection Process And Charts

### *Data collection process*

#### **European Data**

##### *Phase one: South Auckland*

The European interviews (women and men) were done first and spread over the Auckland region. The data collection process began with six European participants (interviews 1-6) in South Auckland. This involved one hospital (Middlemore) and two clinics (Clinic 1 and Clinic 2).<sup>6</sup> Interviews were conducted with one woman and one man from Clinic 1 and subsequently two more interviews (one woman and one man) were conducted at Middlemore hospital. A further two interviews from both sexes were conducted at Clinic 2. These six interviews completed the data collection in the Southern site. The final numbers in each group here: 3 European women's group and 3 European men's group. More details about the groups are given in Chapter Five). Note that the first four of these six interviews were used as pilots to test and modify the interview schedule (see pilot testing in Chapter five for more details). (Note that a schematic representation of this and the following phases is provided in flow chart).

##### *Phase two: Central Auckland*

In the central Auckland locality, eight interviews (interviews 7-14) were conducted four at clinics and four at hospitals. The first two interviews were conducted at Clinic 3 with one woman and one man, followed by two interviews at Green Lane hospital, also with one woman and one man. Two other interviews were conducted at Clinic 4 with one woman and one man. The final set of interviews for the Central site was conducted at Auckland hospital with one woman and one man.

##### *Phase three: West Auckland*

In West Auckland, two interviews were conducted at Clinic 5 with one woman and one man. Then the final interviews for the European participants were conducted at Clinic 6 with one woman and one man.

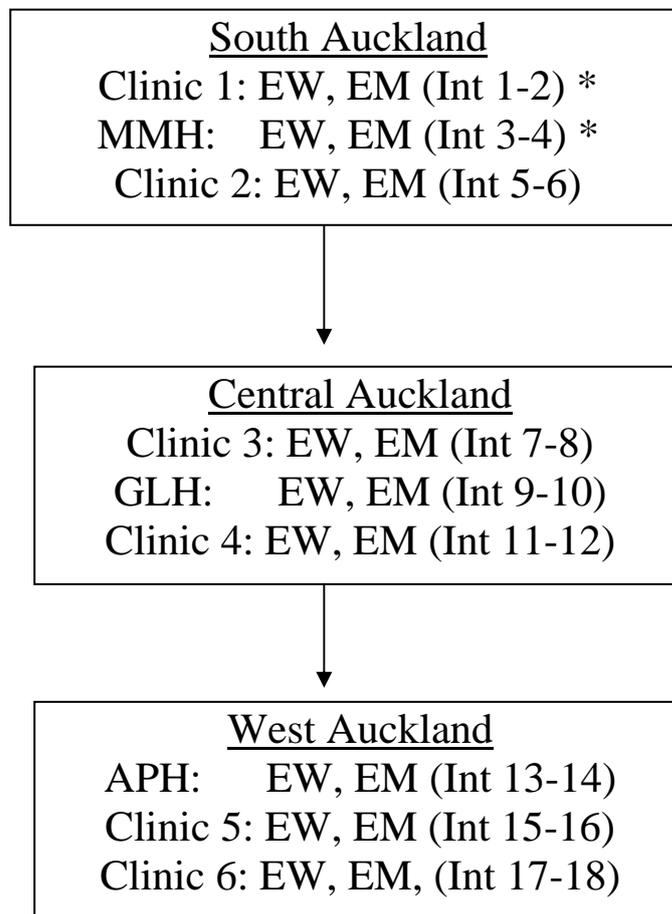
##### *Summary of the European participants*

The above phases provided the first two groups of the overall sample, Group 1 European women and Group 2 European men. The characteristics of these two groups are shown in Appendix K. To summarise, Group 1 consisted of 9 women aged between 57 and 79 years with a mean age of 71.3 years. Their occupations were: one woman was a clerk, one woman was a company director and the seven other women were retired. Group 2 consisted of 9 men aged between 46 and 80 years, with a mean age of 56.4 years. Men's occupations were: a chief executive, a manager, a technician, a caretaker, a model, and two men were retired. The first sample consisted of 18 European participants (nine women and nine men).

---

<sup>6</sup> See Chapter Five for the Selection Criteria and their Justification for the names of clinics participating in the study.

## Data collection chart for European participants



EW, European women; EM, European men; Int, Interview; MMH; Middlemore Hospital; APH, Auckland Public Hospital; GLH, Green Lane Hospital; Clinic, General Practitioners' Medical Centre \* Pilot interviews

## Maori Data

### *Phase four: South Auckland*

After the initial theory was developed, the researcher began to select and analyse the second two groups (Maori women and men who have experienced heart disease symptoms). The Maori data collection process began in South Auckland then moved to Central Auckland and finished in West Auckland. The first interviews with eight Maori participants (interviews 1 to 6, 9, 10) in South Auckland were conducted at Maori Health Trust 1<sup>7</sup> and Middlemore hospital. The first interviews for the Maori participants started with one woman and one man were conducted at Trust 1. A further two interviews with one man and one woman, were conducted at Middlemore hospital. Another two interviews were conducted at Trust 1 with one woman and one man. Then the last two participants were selected from Middlemore hospital. The Maori interviewer decided in consultation with the researcher that Maori participants could choose to be interviewed at home if they felt more comfortable. Two women participants at Middlemore hospital chose this option although one woman later declined an interview at home. The eight interviews made up the data collection for South Auckland. Note that the first four of these interviews were used as pilots to test or alter the interview schedule. More details about the groups are given in Chapter Five. (Note that a schematic representation of this and the following phases is provided in the data flow chart).

### *Phase five: Central Auckland*

In the Central locality six interviews (interviews 7, 8, 11, 12, 13, 14) were conducted at Maori Health Trust 2 and Green Lane hospital. Two interviews with one woman and one man were conducted at Trust 2. Then two further interviews with one woman and one man were conducted at Trust 2. The last two hospital interviews were conducted with one woman who agreed to be interviewed on the ward at Green Lane hospital and one man who decided to be interviewed at home. These six interviews made up the data taken from Central Auckland.

### *Phase six: West Auckland*

In West Auckland four participants (interviews 15, 16, 17, 18) were interviewed at Trust 3. One woman was interviewed first and then one man. A second pair of interviews with one woman and one man completed the data collection from West Auckland.

### *Summary of the Maori participants*

Phases 4, 5 and 6 supplied the second two groups of the total sample. Group 3, Maori women and Group 4, Maori men. The characteristics of Groups 3 and 4 are shown in Appendix K. Group 3 consisted of 9 Maori women aged between 45 and 72 years with a mean age of 59.1 years. Their occupations were: a factory worker, a schoolteacher, three were sickness beneficiaries and four other women were retired. Group 4 comprised of 9 Maori men with ages ranging from 46 years to 81 years with a mean age of 60.4 years. Maori men's occupations were: two men were labourers, one was unemployed, one was self-employed, an invalid beneficiary, a sickness

---

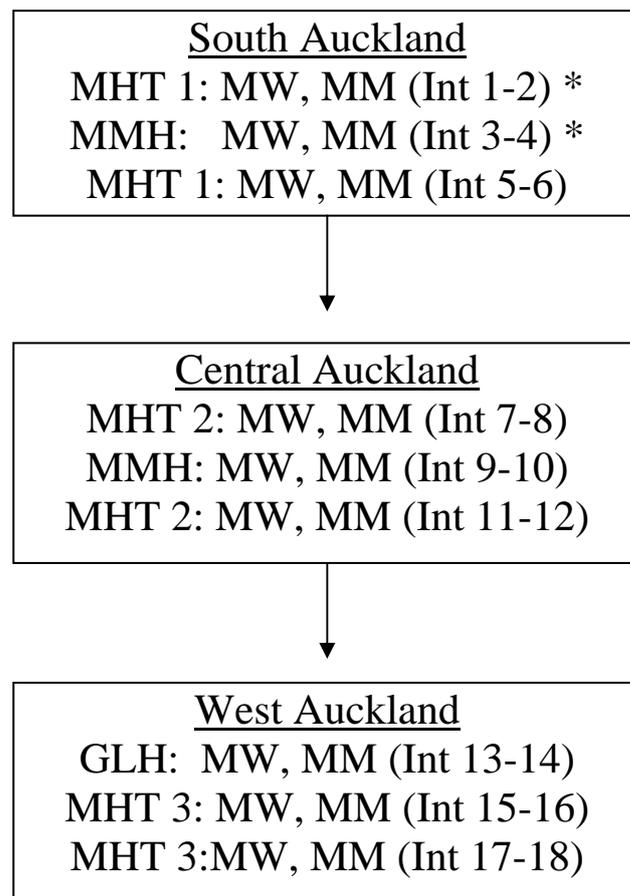
<sup>7</sup> See Chapter Five for the Selection Criteria and their Justification for the names of Maori Health Trusts in each locality.

beneficiary and three other men were retired. The second sample consisted of 17 Maori women and men (eight women and nine men).

*Summary:*

The final sample number was made up of four groups (35 participants), which is illustrated in the profile of participants. See Data flow Chart. There were differences between the four groups. The majority of European participants were older and retired while the Maori participants tended to be younger, employed in physically demanding jobs or unable to work because of chronic illness. Five Maori participants aged over 63 years had reached retirement. The group differences provided the opportunity to compare and contrast a variety of symptom experiences and coping activities surrounding care seeking for heart disease. The sample was dispersed throughout a wide area (Central, West and South Auckland) to provide important contextual information useful in the axial coding phase. The field data from the four groups was used to develop the theory (Creswell, 1998).

**Data collection chart for Maori participants**



MW, Maori women; MM, Maori men; Int, Interview; MMH, Middlemore Hospital; GLH, Green Lane Hospital; MHT, Maori Health Trust, \* Pilot interviews

## APPENDIX M: Preferences For Survival Data Chart

### Identifying The Location Of The Missing Link

<b>Preferences for Survival</b>
-------------------------------------

<b>Initial context</b>
------------------------

<b>Intermittent conditions</b>
------------------------------------

<i>Missing link</i> How do you describe and explain differences in survival strategies?
---

<i>Missing link</i> How do you describe and explain differences in coping strategies?
---

<b>Women</b>	<b>Men</b>	<b>Women</b>	<b>Men</b>
Symptom descriptions	Symptom descriptions	Personal knowledge	Personal knowledge
Maintaining the status quo	Holding the fort	Expectations	Expectations
Obtaining reassurance	Obtaining reassurance	Seek reassurance	Seeking reassurance
Permissible and sanctioned actions			
		Learning new codes	Learning new codes

## LIST OF REFERENCES

- The 2000 Victoria Declaration: Women, heart diseases and stroke: Science and policy in action. (2000). In *The Canadian Women's Health Network*. Retrieved March 21, 2001, from [http://www.cwhn.ca/resources/victoria\\_declaration/](http://www.cwhn.ca/resources/victoria_declaration/)
- Abbott, M. W., & Durie, M. H. (1987). Taha Maori and undergraduate medical training. *New Zealand Medical Journal*, 100(830), 524-527.
- Ahmed, A. K., Hoekstram, M. J., Hagem, J. J., & Karim, R. B. (2003). Honey-medicated dressing: transformation of an ancient remedy into modern therapy. *Annals of Plastic Surgery*, 50(2), 143-147.
- Allan, R., & Scheidt, S. (Eds.). (1996). *Heart and mind: The practice of cardiac psychology*. Washington, DC: American Psychological Association.
- Alonzo, A. A. (1986). The impact of the family and lay others on care-seeking during life-threatening episodes of suspected coronary artery disease. *Social Science & Medicine*, 22(12), 1297-1311.
- Anonymous. (1988). Randomised trial of intravenous streptokinase, oral aspirin, both, or neither among 17,187 cases of suspected acute myocardial infarction: ISIS-2. ISIS-2 (Second International Study of Infarct Survival) Collaborative Group. *Lancet*, 2(8607), 349-360.
- Argyle, M., & Henderson, M. (1985). The rules of relationships. In S. Duck & D. Perlman (Eds.), *Understanding personal relationships: An interdisciplinary approach* (pp. 63-84). London: Sage.
- Ashton, K. C. (1999). How men and women with heart disease seek care: The delay experience. *Progress in Cardiovascular Nursing*, 14(2), 53-60.

- Baker, G. E., & Koelmeyer, T. D. (1999). Death due to unrecognised myocardial infarction causing left ventricular rupture: Can we improve the diagnostic rate? *New Zealand Medical Journal*, *112*(1099), 429-430.
- Barnes, L., Moss-Morris, R., & Kaufusi, M. (2004). Illness beliefs and adherence in diabetes mellitus: A comparison between Tongan and European patients. *New Zealand Medical Journal*, *117*(1188), 1-9.
- Baumann, L. J., Cameron, L. D., Zimmerman, R. S., & Leventhal, H. (1989). Illness representations and matching labels with symptoms. *Health Psychology*, *8*(4), 449-469.
- Beaglehole, R., Bonita, R., & Kjellstrom, T. (1993). *Basic epidemiology*. Geneva, Switzerland: World Health Organization.
- Bell, C., Swinburn, B., Stewart, A., Jackson, R., Tukuitonga, C., & Tipene-Leach, D. (1996). Ethnic differences and recent trends in coronary heart disease incidence in New Zealand. *New Zealand Medical Journal*, *109*(1017), 66-68.
- Bett, N., Aroney, G., & Thompson, P. (1993). Impact of a national educational campaign to reduce patient delay in possible heart attack. *Australian & New Zealand Journal of Medicine*, *23*(2), 157-161.
- Blakely, T., & Dew, K. (2004). Ethnicity, acculturation and health: Who's to judge? *New Zealand Medical Journal*, *117*(1188), 1-3.
- Bleeker, J. K., & Erdman, R. A. (1991). Delay of help-seeking by patients with an acute myocardial infarction. *Gedrag & Gezondheid: Tijdschrift voor Psychologie & Gezondheid*, *19*(6), 289-301.
- Bleeker, J. K., Lamers, L. M., Leenders, I. M., Kruyssen, D. C., Simoons, M. L., Trijsburg, R. W., et al. (1995). Psychological and knowledge factors related to delay of help-seeking by patients with acute myocardial infarction. *Psychotherapy & Psychosomatics*, *63*(3-4), 151-158.

- Bonita, R. (2000, May 8-10). *World Health Organisation mandate for women and heart diseases*. Paper presented at the International Conference on Women, Heart Diseases and Stroke, Victoria, Canada.
- Bronfen, E. (1992). Preparation for an autopsy. In *Over her dead body: Death, femininity and the aesthetic* (pp. 3-14). Manchester, England: Manchester University Press.
- Buchan, I. (1975). *The history of Campbell*. Comrie, Perthshire, Scotland: Scottish Tartan Society.
- Bullen, C. (1997). *Ethnic differences in coronary heart disease case fatality in Auckland*. Unpublished dissertation, University of Auckland, Auckland, New Zealand.
- Burgess, C., Hunter, M. S., & Ramirez, A. J. (2001). A qualitative study of delay among women reporting symptoms of breast cancer. *British Journal of General Practice*, 51(473), 967-971.
- Cameron, L. (1997). Screening for cancer: Illness perceptions and illness worry. In K. J. Petrie & J. A. Weinman (Eds.), *Perceptions of health and illness current research and applications*. Amsterdam: Harwood Academic Publishers.
- Cameron, L., Leventhal, E. A., & Leventhal, H. (1993). Symptom representations and affect as determinants of care seeking in a community-dwelling, adult sample population. *Health Psychology*, 12(3), 171-179.
- Cameron, L., Leventhal, E. A., & Leventhal, H. (1995). Seeking medical care in response to symptoms and life stress. *Psychosomatic Medicine*, 57(1), 37-47.
- Campbell, C. (1998). *Why people hesitate to seek medical care for heart attack symptoms*. Unpublished master's thesis, University of Auckland, Auckland, New Zealand.

- Charmaz, K. (1990). Discovering chronic illness: Using grounded theory. *Social Science & Medicine*, 30(11), 1161-1172.
- Chodrow, N. (1995). Gender as personal and cultural construction. *Signs, Spring*, 516-544.
- Chodrow, N. (2002). Gender as a personal and cultural construction. In M. Dimen & V. Goldner (Eds.), *Gender in psychoanalytic space: Between clinic and culture* (pp. 237-261). New York: Other Press.
- Ciofu Baumann, L. (2003). Culture and illness representation. In L. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 242-253). London: Routledge.
- Cooper, R. S., Simmons, B., Castaner, A., Prasad, R., Franklin, C., & Ferlinz, J. (1986). Survival rates and prehospital delay during myocardial infarction among black persons. *American Journal of Cardiology*, 57(4), 208-211.
- Cox, J. L., Lee, E., Langer, A., Armstrong, P. W., & Naylor, C. D. (1997). Time to treatment with thrombolytic therapy: determinants and effect on short-term nonfatal outcomes of acute myocardial infarction. Canadian GUSTO Investigators. Global Utilization of Streptokinase and + PA for Occluded Coronary Arteries. *CMAJ (Canadian Medical Association Journal)*, 156(4), 497-505.
- Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage Publications.
- de Pisan, C. (1982). *The book of the city of ladies* (E. J. Richards, Trans.). New York: Persea Books.
- Dempsey, S. J., Dracup, K., & Moser, D. K. (1995). Women's decision to seek care for symptoms of acute myocardial infarction. *Heart & Lung: Journal of Critical Care*, 24(6), 444-456.

- DeVon, H. A., & Zerwic, J. J. (2002). Symptoms of acute coronary syndromes: Are there gender differences? A review of the literature. *Heart & Lung: Journal of Acute & Critical Care*, 31(4), 235-245.
- Doggen, C., van der Palen, J., & Beaglehole, R. (1993). Trends in medical management of acute myocardial infarction, Auckland 1983-90. *New Zealand Medical Journal*, 106, 278-281.
- Dracup, K., McKinley, S. M., & Moser, D. K. (1997). Australian patients' delay in response to heart attack symptoms. *Medical Journal of Australia*, 166(5), 233-236.
- Dracup, K., Moser, D. K., Eisenberg, M., Meischke, H., Alonzo, A. A., & Braslow, A. (1995). Causes of delay in seeking treatment for heart attack symptoms. *Social Science & Medicine*, 40(3), 379-392.
- Durie, M. (1994). *Whaiora: Māori health development*. Auckland, New Zealand: Oxford University Press.
- Durie, M. (1999). *Paiheretia - An integrated approach to counselling*. Paper presented at the 25th Anniversary Conference - New Zealand Association of Counsellors.
- Durie, M. (2001). *Mauri ora: The dynamics of Māori health*. Auckland, New Zealand: Oxford University Press.
- Durie, M. H. (1977). Maori attitudes to sickness, doctors and hospitals. *New Zealand Medical Journal*, 86(600), 483-485.
- Durie, M. H. (1985). A Maori perspective of health. *Social Science & Medicine*, 20(5), 483-486.
- Durie, M. H. (1999). Kaumatautanga reciprocity: Maori elderly and whanau. *New Zealand Journal of Psychology*, 28(2), 103-107.

- Egan, G. (1990). *The skilled helper: A systematic approach to effective helping* (4th ed.). Belmont, CA: Brooks/Cole Publishing Co.
- Ell, K., & Dunkel-Schetter, C. (1994). Social support and adjustment to myocardial infarction, angioplasty, and coronary artery bypass surgery. In S. A. Shumaker & S. M. Czajkowski (Eds.), *Social support and cardiovascular disease: Plenum series in behavioral psychophysiology and medicine* (pp. 301-332). New York: Plenum Press.
- Ell, K., Haywood, L. J., deGuzman, M., Sobel, E., Norris, S., Blumfield, D., et al. (1995). Differential perceptions, behaviors, and motivations among African Americans, Latinos, and whites suspected of heart attacks in two hospital populations. *Journal of the Association for Academic Minority Physicians*, 6(2), 60-69.
- Ell, K., Haywood, L. J., Sobel, E., deGuzman, M., Blumfield, D., & Ning, J. P. (1994). Acute chest pain in African-Americans: Factors in the delay in seeking emergency care. *American Journal of Public Health*, 84(6), 965-970.
- Ellis, R. (1998). *He rato tapuhi: Maternity services for Māori women*. Hamilton: Waikato Print.
- Farmer, P. (1994). AIDS-talk and the constitution of cultural models. *Social Science & Medicine*, 38(6), 801-809.
- Fisher, J. (1996). Is there a need for cardiac psychology? The view of a practicing cardiologist. In R. Allan & S. Scheidt (Eds.), *Heart & Mind: The practice of cardiac psychology* (pp. 125-145). Washington, DC: American Psychological Association.
- Fontana, A., & Fray, J. (1994). Interviewing: The art of science. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 361-376). Thousand Oaks, CA: Sage Publications.

- Fowler, H. W., & Fowler, F. G. (1962). *The concise oxford dictionary of current english* (7th ed.). Oxford, England: Clarendon Press.
- Friedman, M., & Rosenman, R. (1959). Association of specific overt behaviour pattern with blood and cardiovascular findings. *Journal of the American Medical Association*, *169*(12), 1287-1296.
- Garro, L. C. (1988). Explaining high blood pressure: Variation in knowledge about illness. *American Ethnologist*, *15*(1), 98-119.
- Ghali, J. K., Cooper, R. S., Kowatly, I., & Liao, Y. (1993). Delay between onset of chest pain and arrival to the coronary care unit among minority and disadvantaged patients. *Journal of the National Medical Association*, *85*(3), 180-184.
- Gibler, W. B., Armstrong, P. W., Ohman, E. M., Weaver, W. D., Stebbins, A. L., Gore, J. M., et al. (2002). Persistence of delays in presentation and treatment for patients with acute myocardial infarction: The GUSTO-I and GUSTO-III experience. *Annals of Emergency Medicine*, *39*(2), 123-130.
- Glaser, B. G. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory; strategies for qualitative research*. Chicago: Aldine Pub. Co.
- Goldberg, R. J., Gurwitz, J., Yarzebski, J., Landon, J., Gore, J. M., Alpert, J. S., et al. (1992). Patient delay and receipt of thrombolytic therapy among patients with acute myocardial infarction from a community-wide perspective. *American Journal of Cardiology*, *70*(4), 421-425.
- Goldberg, R. J., O'Donnell, C., Yarzebski, J., Bigelow, C., Savageau, J., & Gore, J. M. (1998). Sex differences in symptom presentation associated with acute myocardial infarction: A population-based perspective. *American Heart Journal*, *136*(2), 189-195.

- Gorman, C. (2003, April 28). The No. 1 killer of women. *Time*, 161, 47-52.
- Grant, V., & Hawken, S. (2000). What do they think of it now? Medical graduates' views of earlier training in communication skills. *Medical Teacher*, 22(3), 260-263.
- Grassi, J. A. (1985). Heart imagery: Some new directions in healing and psychotherapeutic applications. *Journal of Mental Imagery*, 9(4), 17-32.
- Griffiths, M. D., & Macdonald, H. F. (1999). Counselling in the treatment of pathological gambling: An overview. *British Journal of Guidance & Counselling*, 27(2), 179-190.
- Gurwitz, J. H., McLaughlin, T. J., Willison, D. J., Guadagnoli, E., Hauptman, P. J., Gao, X., et al. (1997). Delayed hospital presentation in patients who have had acute myocardial infarction. *Annals of Internal Medicine*, 126(8), 593-599.
- Hackett, T., & Cassem, N. (1972). Factors contributing to delay in responding to the signs and symptoms of acute myocardial infarction. *Am J Cardiol*, 30, 476-482.
- Hackett, T. P., & Cassem, N. H. (1975). Psychological management of the myocardial infarction patient. *Journal of Human Stress*, 1(3), 25-38.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology & Health*, 18(2), 141-184.
- Harvey, W. (1965). A second disquisition to John Riolan, Jun., in which many objections to the circulation of the blood are refuted (R. Willis, Trans.). In *The works of William Harvey* (pp. 108-141). New York: Johnson Reprint Corporation.
- Hay, D. R. (1993). Campaigning for health. *Australian & New Zealand Journal of Medicine*, 23(2), 146-147.

- Helman, C. (1994). *Culture, health and illness* (3rd ed.). Oxford: Butterworth-Heinemann.
- Herd, R., & Raeburn, J. (2003). *Gambling and public health: A workplan*. Auckland, New Zealand: Problem Gambling Foundation of New Zealand and Hapai te Hauroa te Tapui Ltd.
- Herlitz, J. (1996). The importance of reducing delay in acute myocardial infarction. *European Heart Journal*, 17(3), 338-340.
- Hofgren, K., Bondestam, E., Johansson, F. G., Jern, S., Herlitz, J., & Holmberg, S. (1988). Initial pain course and delay to hospital admission in relation to myocardial infarct size. *Heart & Lung*, 17(3), 274-280.
- Hofstede, G. H. (1998). The cultural construction of gender. In G. H. Hofstede (Ed.), *Masculinity and femininity: The taboo dimension of national cultures* (pp. 77-105). Thousand Oaks, CA: Sage Publications.
- Horne, R., James, D., Petrie, K., Weinman, J., & Vincent, R. (2000). Patients' interpretation of symptoms as a cause of delay in reaching hospital during acute myocardial infarction. *Heart*, 83(4), 388-393.
- Horne, R., & Weinman, J. (1999). Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of Psychosomatic Research*, 47(6), 555-567.
- Johnson, S. L. (1970). *The history of cardiac surgery 1896-1955*. Baltimore, MD: Johns Hopkins Press.
- Jones, P. M. (1998). *Medieval medicine in illuminated manuscripts* (Rev ed.). London: British Library.
- Julian, D. G., & Wenger, N. K. (Eds.). (1997). *Women and heart disease*. London: Martin Dunitz.

- Kahukiwa, R. (1995). *Robyn Kahukiwa: Works from 1985-1995*. Wellington, New Zealand: Bowen Galleries.
- Kay, M. A. (1993). Fallen fontanelle: Culture-bound or cross-cultural? *Medical Anthropology*, 15(2), 137-156.
- Keller, M. L., Leventhal, H., Prohaska, T. R., & Leventhal, E. A. (1989). Beliefs about aging and illness in a community sample. *Research in Nursing & Health*, 12(4), 247-255.
- Kelly, P. (1999). Isolation and stigma: The experience of patients with active tuberculosis. *Journal of Community Health*, 16(4), 233-241.
- Kelly-Powell, M. L. (1997). Personalizing choices: Patients' experiences with making treatment decisions. *Research in Nursing & Health*, 20(3), 219-227.
- Kenyon, L. W. (1990). *Psychological factors related to delay in seeking treatment for symptoms of acute myocardial infarction*. Unpublished doctoral dissertation, Wayne State University, Detroit, MI.
- Kenyon, L. W., Ketterer, M. W., Gheorghide, M., & Goldstein, S. (1991). Psychological factors related to prehospital delay during acute myocardial infarction. *Circulation*, 84(5), 1969-1976.
- Kenyon, L. W., Ketterer, M. W., Gheorghide, M., & Goldstein, S. (1992). Delay in response to acute myocardial infarction. *Circulation*, 85(6), 2333.
- Khaw, K. (1997). Epidemiology of coronary heart disease in women. In D. Julian & N. Wenger (Eds.), *Women and heart disease* (pp. 7-20). London: Martin Dunitz.
- Kidd, J., & Wix, L. (1996). Images of the heart: Archetypal imagery in therapeutic artwork. *Art Therapy*, 13(2), 108-113.
- Kitzinger, S. (1985). *Woman's experience of sex*. New York: Penguin.

- Klapisch-Zuber, C. (1985). The "cruel mother" maternity, widowhood, and dowry in Florence in the fourteenth and fifteenth centuries. In *Women, family and ritual in Renaissance Italy* (pp. 117-131). Chicago: The University of Chicago Press.
- Kleinman, A., Wang, W., Li, S., Cheng, M., Dai, X., & Kleinman, J. (1995). The social course of epilepsy: Chronic illness as social experience. *Social Science & Medicine*, 40(10), 1319-1330.
- Kolitz, S., Antoni, M., & Green, C. (1988). Personality style and immediate help-seeking responses following the onset of myocardial infarction. 2(Psychology & health), 259-289.
- Koopman-Boyden, P. (1993). *Introduction, In New Zealand's Ageing Society: The Implications.*: Daphne Brasell Associates Press, Wellington.
- Kottler, J. A., & Blau, D. S. (1989). Being a Reflective Therapist. In *The imperfect therapist: Learning from failure in therapeutic practice* (pp. 149-181). San Francisco: Jossey-Bass.
- Landrine, H., & Klonoff, E. (2001). Cultural diversity and health psychology. In A. Baum, T. A. Revenson & J. E. Singer (Eds.), *Handbook of Health Psychology* (pp. 851-891). Mahwah, NJ: Lawrence Erlbaum Associates.
- Le Goff, J. (1989). Head or heart? The political use of body metaphors in the middle ages. In M. Feher, R. Naddaaff & N. Tazi (Eds.), *Fragments for a history of the human body* (Vol. 3, pp. 12-27). New York: Zone.
- Legato, M., Padus, E., & Slaughter, E. (1997). Women's perceptions of their general health, with special reference to their risk of coronary heart disease: Results of a national telephone survey. *Journal of Women's Health*, 6(2), 189-198.
- Leizorovicz, A., Haugh, M. C., Mercier, C., & Boissel, J. P. (1997). Pre-hospital and hospital time delays in thrombolytic treatment in patients with suspected acute myocardial infarction: Analysis of data from the EMIP study: European Myocardial Infarction Project. *European Heart Journal*, 18(2), 248-253.

- Leslie, W. S., Urie, A., Hooper, J., & Morrison, C. E. (2000). Delay in calling for help during myocardial infarction: reasons for the delay and subsequent pattern of accessing care. *Heart*, *84*(2), 137-141.
- Leventhal, E. A., & Crouch, M. (1997). Are there differences in perceptions of illness across the lifespan? In K. J. Petrie & J. A. Weinman (Eds.), *Perceptions of health and illness current research and applications*. Amsterdam: Harwood Academic Publishers.
- Leventhal, E. A., Easterling, D., Leventhal, H., & Cameron, L. (1995). Conservation of energy, uncertainty reduction, and swift utilization of medical care among the elderly: Study II. *Medical Care*, *33*(10), 988-1000.
- Leventhal, E. A., Leventhal, H., Shacham, S., & Easterling, D. V. (1989). Active coping reduces reports of pain from childbirth. *Journal of Consulting and Clinical Psychology*, *57*(3), 365-371.
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., Patrick-Miller, L., et al. (1997). Illness representations: Theoretical foundations. In K. J. Petrie & J. A. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 19-45). Amsterdam: Harwood Academic Publishers.
- Leventhal, H., & Cameron, L. (1987). Behavioural theories and the problem of compliance. *Patient Education & Counseling*, *10*, 117-138.
- Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy & Research*, *16*(2), 143-163.
- Leventhal, H., Leventhal, E. A., & Cameron, L. (1999). Representations, procedures and affect in illness self regulation: A perceptual-cognitive model. In A. Baum, T. A. Revenson & H. Wein (Eds.), *Handbook of Health Psychology*. New York: Earlbaum.

- Luepker, R. V., Apple, F. S., Christenson, R. H., Crow, R. S., Fortmann, S. P., Goff, D., et al. (2003). Case definitions for acute coronary heart disease in epidemiology and clinical studies. *Circulation*, *108*(20), 2543-2549.
- Lumpkin, J. R., Glower, J. J., Fineberg, H., & Jekel, J. (1986). Community perceptions of appropriate sources of emergency care. *Annals of Emergency Medicine*, *15*(2), 191-195.
- Margotta, R. (1967). *An illustrated history of medicine*. Middlesex, England: Hamlyn Publishing Group.
- Martin, R., & Suls, J. (2003). How gender stereotypes influence self-regulation of cardiac health care-seeking and adaptation. In L. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 220-241). New York: Routledge.
- Mayou, R. A., & Thompson, D. R. (2002). Treatment needs of patients admitted for acute chest pain. *Journal of Psychosomatic Research*, *53*(6), 1177-1183.
- Mays, N., & Pope, C. (1995). Rigour and qualitative research. *BMJ*, *311*(6997), 109-112.
- McKinlay, J. (1996). Some contributions from the social systems to gender inequalities in heart disease. *Journal of Health and Social Behaviour*, *37*, 1-26.
- McKinlay, J. B., Potter, D. A., & Feldman, H. A. (1996). Non-medical influences on medical decision-making. *Social Science & Medicine*, *42*(5), 769-776.
- McKinley, S., Moser, D. K., & Dracup, K. (2000). Treatment-seeking behavior for acute myocardial infarction symptoms in North America and Australia. *Heart & Lung: Journal of Acute & Critical Care*, *29*(4), 237-247.
- McMahon, C. E. (1976). The psychosomatic approach to heart disease: A study in premodern medicine. *Chest*, *69*(4), 531-537.

- McSweeney, J. C., & Crane, P. B. (2000). Challenging the rules: Women's prodromal and acute symptoms of myocardial infarction. *Research in Nursing & Health*, 23(2), 135-146.
- Meischke, H., Dulberg, E. M., Schaeffer, S. S., Henwood, D. K., Larsen, M. P., & Eisenberg, M. S. (1997). Call fast, call 911 - a direct mail campaign to reduce patient delay in acute myocardial infarction. *American Journal of Public Health*, 87(10), 1705-1709.
- Meischke, H., Eisenberg, M. S., & Larsen, M. P. (1993). Prehospital delay interval for patients who use emergency medical services: the effect of heart-related medical conditions and demographic variables. *Annals of Emergency Medicine*, 22(10), 1597-1601.
- Meischke, H., Eisenberg, M. S., Schaeffer, S. M., Damon, S. K., Larsen, M. P., & Henwood, D. K. (1995). Utilization of emergency medical services for symptoms of acute myocardial infarction. *Heart & Lung*, 24(1), 11-18.
- Meischke, H., Eisenberg, M. S., Schaeffer, S. M., Larsen, M. P., & et al. (1994). Impact of direct mail intervention on knowledge, attitudes, and behavioral intentions regarding use of emergency medical services for symptoms of acute myocardial infarction. *Evaluation & the Health Professions*, 17(4), 402-417.
- Meischke, H., Ho, M. T., Eisenberg, M. S., Schaeffer, S. M., & Larsen, M. P. (1995). Reasons patients with chest pain delay or do not call 911. *Annals of Emergency Medicine*, 25(2), 193-197.
- Meischke, H., Larsen, M. P., & Eisenberg, M. S. (1998). Gender differences in reported symptoms for acute myocardial infarction: Impact on prehospital delay time interval. *American Journal of Emergency Medicine*, 16(4), 363-366.

- Meischke, H., Sellers, D. E., Robbins, M. L., Goff, D. C., Daya, M. R., Meshack, A., et al. (2000). Factors that influence personal perceptions of the risk of an acute myocardial infarction. *Behavioral Medicine*, 26(1), 4-13.
- Merz, C. N., Kelsey, S. F., Pepine, C. J., Reichek, N., Reis, S. E., Rogers, W. J., et al. (1999). The Women's Ischaemia Syndrome Evaluation (WISE) study: Protocol design, methodology and feasibility report. *Journal of the American College of Cardiology*, 33(6), 1453-1461.
- Meyer, D., Leventhal, H., & Gutmann, M. (1985). Common-sense models of illness: The example of hypertension. *Health Psychology*, 4(2), 115-135.
- Milgrom, J. (1985). When is a heart not a heart? *Journal of Mental Imagery*, 9(4), 57-69.
- Miller, A. (2001). *Conditions of faith*. St. Leonards, NSW, Australia: Allen & Unwin.
- Miller, C. L. (2000). Cue sensitivity in women with cardiac disease. *Progress in Cardiovascular Nursing*, 15(3), 82-89.
- Miller, C. L., & Kollauf, C. R. (2002). Evolution of information on women and heart disease 1957-2000: A review of archival records and secular literature. *Heart & Lung: Journal of Acute & Critical Care*, 31(4), 253-261.
- Mosca, L., Appel, L. J., Benjamin, E. J., Berra, K., Chandra-Strobos, N., Fabunmi, R. P., et al. (2004). Evidence-based guidelines for cardiovascular disease prevention in women. *Circulation*, 109(5), 672-693.
- Moss-Morris, R., Petrie, K., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? *British Journal of Health Psychology*, 1(1), 15-25.
- Murray, C., & Lopez, M. (Eds.). (1996). *The global burden of disease: A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020*. Cambridge, MA: Harvard

School of Public Health on behalf of the World Health Organization and the World Bank.

- Murray, M., & Chamberlain, K. (Eds.). (1999). *Qualitative health psychology: Theories and methods*. London: Sage Publications.
- Naidoo, J., & Wills, J. (2000). Influences on health. In *Health promotion: Foundations for practice* (2nd ed., pp. 27-50). New York: Baillière Tindall.
- New Zealand Department of Statistics. (1996). *New Zealand Census 1996: Question on Ethnicity: The Census of Population and Dwellings: Question 10: .* Wellington, New Zealand: Department of Statistics.
- New Zealand Ministry of Health. (2000). *The New Zealand health strategy*. Wellington, New Zealand: Ministry of Health.
- New Zealand Ministry of Health. (2002). He korowai oranga: Māori health strategy. In Retrieved June 3, 2003, from [http://www.moh.govt.nz/moh.nsf/0/8221e7d1c52c9d2ccc256a37007467df/\\$FILE/mhs-english.pdf](http://www.moh.govt.nz/moh.nsf/0/8221e7d1c52c9d2ccc256a37007467df/$FILE/mhs-english.pdf)
- New Zealand Ministry of Health. (2003). Mortality and demographic data 1999. In *New Zealand Health Information Service Publications*. Retrieved March 3, 2004, from <http://www.nzhis.govt.nz/publications/Mortality.html>
- Nolan, R. P., & Wielgosz, A. T. (1991). Assessing adaptive and maladaptive coping in the early phase of acute myocardial infarction. *Journal of Behavioral Medicine, 14*(2), 111-124.
- Norris, R. (1999). *Sudden cardiac death and acute myocardial infarction in three British health districts: The UK heart attack study*. Brighton, England: British Heart Foundation.

- Norris, R. M. (1992). An overview of trials establishing that thrombolytic therapy improves outcome in patients with acute myocardial infarction. *Coronary Artery Disease*, 3(2), 96-102.
- Oakley, A. (1976). Wise woman and medicine man: Changes in the management of childbirth. In J. Mitchell & A. Oakley (Eds.), *The rights and wrongs of women* (pp. 17-58). Harmondsworth, New York: Penguin.
- Oakley, A. (1981). Interviewing women: A contradiction in terms. In H. Roberts (Ed.), *Doing feminist research* (pp. 30-61). London: Routledge & Kegan Paul.
- Orsman, H., & Hurley, D. (Eds.). (1992). *Quotable New Zealanders: Memorable remarks & reflections*. Auckland, New Zealand: Reed Books.
- Orth-Gomer, K., & Chesney, M. (1997). Social stress/strain and heart disease in women. In D. Julian & N. Wenger (Eds.), *Women and heart disease* (pp. 407-420). London: Martin Dunitz Ltd.
- Osler, W. (1910). Lumleian lectures on angina pectoris. *Lancet*, 1, 839-844.
- Osler, W. (1967). *Osler's textbook revisited*. New York: Meredith Publishing Company.
- Ottesen, M. M., Dixen, U., Torp-Pedersen, C., & Kober, L. (2003). Prehospital behaviour of patients admitted with acute coronary syndrome or witnessed cardiac arrest. *Scandinavian Cardiovascular Journal*, 37(3), 141-148.
- Ottesen, M. M., Kober, L., Jorgensen, S., & Torp-Pedersen, C. (1996). Determinants of delay between symptoms and hospital admission in 5978 patients with acute myocardial infarction. *European Heart Journal*, 17(3), 429-437.
- Patcher, L. M. (1994). Culture and clinical care. Folk illness beliefs and behaviors and their implications for health care delivery. *JAMA*, 271(9), 690-694.

- Pattenden, J., Watt, I., Lewin, R. J., & Stanford, N. (2002). Decision making processes in people with symptoms of acute myocardial infarction: Qualitative study. *BMJ*, *324*(7344), 1006-1009.
- Perry, K., Petrie, K. J., Ellis, C. J., Horne, R., & Moss-Morris, R. (2001). Symptom expectations and delay in acute myocardial infarction patients. *Heart*, *86*(1), 91-92.
- Petrie, K. J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: Longitudinal study. *BMJ*, *312*(7040), 1191-1194.
- Petrie, K. J., & Weinman, J. A. (1997). Illness representations and recovery from myocardial infarction. In K. J. Petrie & J. A. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 441-461). Amsterdam: Harwood Academic Publishers.
- Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research*, *8*(3), 341-351.
- Quotable New Zealand women*. (1994). Auckland, New Zealand: Reed.
- Raczynski, J. M., Finnegan, J. R., Zapka, J. G., Meischke, H., Meshack, A., Stone, E. J., et al. (1999). REACT theory-based intervention to reduce treatment-seeking delay for acute myocardial infarction. *American Journal of Preventive Medicine*, *16*(4), 325-334.
- Raeburn, J., & Rootman, I. (1998). *People-centred health promotion*. Chichester, England: John Wiley.
- Ramm, C., Robinson, S., & Sharpe, N. (2001). Factors determining non-attendance at a cardiac rehabilitation programme following myocardial infarction. *New Zealand Medical Journal*, *114*(1132), 227-229.

- Rawles, J. M., & Haites, N. E. (1988). Patient and general practitioner delays in acute myocardial infarction. *BMJ*, 296(6626), 882-884.
- Rawles, J. M., Metcalfe, M. J., Shirreffs, C., Jennings, K., & Kenmure, A. C. (1990). Association of patient delay with symptoms, cardiac enzymes, and outcome in acute myocardial infarction. *European Heart Journal*, 11(7), 643-648.
- Reichbart, R. (1981). Heart symbolism: The heart-breast and heart-penis equations. *Psychoanalytic Review*, 68(1), 75-104.
- Reichbart, R. H. (1983). *Heart symbolism: An investigation into psychoanalytic symbolism as applied to the heart*. Unpublished doctoral dissertation, City University of New York.
- Robbins, S. (1991). Organisational Behaviour In A Global Context. In *Organisational Behaviour: Concepts, Controversies and Applications* (Fifth ed., pp. 54-72): Prentice- Hall International Editions, New Jersey, USA.
- Roger, V., & Gersh, B. (1997). Myocardial Infarction. In D. Julian & N. Wenger (Eds.), *Women and heart disease* (pp. 136-150). London: Martin Dunitz Ltd.
- Rose, G. (1962). The diagnosis of ischaemic heart pain and intermittent claudication in field surveys. *Bulletin of the World Health Organization*, 27, 645-658.
- Rowley, H. (1958). *Vocabulary of the Bible*: Lutterworth Press, London.
- Ruston, A., Clayton, J., & Calnan, M. (1998). Patients' action during their cardiac event: qualitative study exploring differences and modifiable factors. *BMJ*, 316(7137), 1060-1064.
- Ryan, C. J., & Zerwic, J. J. (2003). Perceptions of symptoms of myocardial infarction related to health care seeking behaviors in the elderly. *Journal of Cardiovascular Nursing*, 18(3), 184-196.

- Safer, M. A., Tharps, Q. J., Jackson, T. C., & Leventhal, H. (1979). Determinants of three stages of delay in seeking care at a medical clinic. *Medical Care*, 17(1), 11-29.
- Sanne, H., & Wenger, N. K. (1992). *Psychologic and social aspects of coronary heart disease: Information for the clinicians*. Darien, CT: International Society and Federation of Cardiology, Le Jacq Communications, Inc.
- Sarantakos, S. (1993). Part 1: Introduction - Social Research: An historical overview. In *Social Research* (pp. 2-21, 27-28). Melbourne, Australia: MacMillan Education Australia Pty Ltd.
- Scherck, K. A. (1997). Recognizing a heart attack: The process of determining illness. *American Journal of Critical Care*, 6(4), 267-273.
- Schoenberg, N. E., Peters, J. C., & Drew, E. M. (2003). Unravelling the mysteries of timing: Women's perceptions about time to treatment for cardiac symptoms. *Social Science & Medicine*, 56(2), 271-284.
- Sharp, I. (1998). Gender issues in the prevention and treatment of coronary heart disease. In L. Doyal (Ed.), *Women and Health Services: An agenda for change* (pp. 101-111). Philadelphia: Open University Press.
- Shroff, F. (1997). Introduction: Midwifery- from rebellion to regulation: The rebirth of an ancient calling. In F. M. Shroff (Ed.), *The new midwifery: Reflections on renaissance and regulation* (pp. 15-37). Toronto, Canada: Women's Press.
- Sonke, G., Beaglehole, R., Jackson, R., Stewart, A., & Stewart, F. (1996). Sex differences in pre-and post- hospital admission case fatality after myocardial infarction. *BMJ*, 313, 853-855.
- SoRelle, R. (1999). Women's heart problems are poorly understood. *Circulation*, 100(24), e114.

- Spelman, E. (1982). Woman as body: Ancient and contemporary views. *Feminist Studies*, 8(1), 109-131.
- The status of women in New Zealand 2002: The fifth report on New Zealand's progress on implementing the United Nations Convention on the Elimination of All forms of Discrimination Against Women.* (2002). Wellington, New Zealand: Ministry of Women's Affairs.
- Stewart, M. (1995). Introduction:. In M. Stewart, J. B. Brown, W. Weston, I. R. McWhinney, C. L. McWilliam & T. R. Freeman (Eds.), *Patient-centered medicine: Transforming the clinical method* (pp. ix-xv). Thousand Oaks, CA: Sage Publicaitons.
- Stewart, M., Brown, J. B., & McWhinney, I. R. (1989). The fifth component enhancing the patient-doctor relationship. In M. Stewart, J. B. Brown, W. Weston, I. R. McWhinney, C. L. McWilliam & T. R. Freeman (Eds.), *Patient-centred medicine: Transforming the clinical method* (pp. 89-98). Thousand Oaks, CA: Sage Publications.
- Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Svensson, L., Karlsson, T., Nordlander, R., Wahlin, M., Zedigh, C., & Herlitz, J. (2003). Safety and delay time in prehospital thrombolysis of acute myocardial infarction in urban and rural areas in Sweden. *American Journal of Emergency Medicine*, 21(4), 263-270.
- Tavares, H., Zilberman, M. L., & el-Guebaly, N. (2003). Are there cognitive and behavioural approaches specific to the treatment of pathological gambling? *Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie*, 48(1), 22-27.

- Thomas, D. R. (2003). A general inductive approach for qualitative data analysis. In Retrieved October 23, 2003, from <http://www.health.auckland.ac.nz/hrmas/resources/Inductive2003.pdf>
- Tod, A. M., Read, C., Lacey, A., & Abbott, J. (2001). Barriers to uptake of services for coronary heart disease: Qualitative study. *BMJ*, *323*(7306), 214.
- Ussher, J. (1999). Feminist approaches to qualitative health research. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 99-113). London: Sage Publications.
- Walker, R. (1990). *Struggle without end - Ka whawhai tonu matou*. Auckland, New Zealand: Penguin.
- Weaver, W., Wilcox, R., Morris, D., Woodlief, L., Gore, J., & White, H. (1993). GUSTO Investigators. Women in GUSTO: Baseline characteristics and effect of treatment regimen on mortality and complication rates. *Circulation*, *88*(part 2), 1-508.
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. *Psychology & Health*, *11*(3), 431-445.
- Weinman, J., Petrie, K. J., Sharpe, N., & Walker, S. (2000). Causal attributions in patients and spouses following first-time myocardial infarction and subsequent lifestyle changes. *British Journal of Health Psychology*, *5*(3), 263-273.
- Wenger, N. (1997). Coronary heart disease in women: Evolving knowledge is dramatically changing clinical care. In D. Julian & N. Wenger (Eds.), *Women and heart disease* (pp. 21-38). London: Martin Dunitz.
- Wenger, N. (1998). An update on coronary heart disease in women. *International Journal of Fertility*, *43*, 84-90.

- Wenger, N. (2002). Coronary heart disease and women: Magnitude of the problem. *Cardiology in Review, 10*, 211-213.
- Wenger, N. K. (2002). Coronary heart disease and women: magnitude of the problem. *Cardiology in Review, 10*(4), 211-213.
- Wielgosz, A. T., Nolan, R. P., Earp, J. A., Biro, E., & Wielgosz, M. B. (1988). Reasons for patients' delay in response to symptoms of acute myocardial infarction. *CMAJ: Canadian Medical Association journal, 139*(9), 853-857.
- Wiles, R. (1998). Patients' perceptions of their heart attack and recovery: The influence of epidemiological "evidence" and personal experience. *Social Science & Medicine, 46*(11), 1477-1486.
- Wood, C. T. (1981). The doctors' dilemma: sin, salvation, and the menstrual cycle in medieval thought. *Speculum-A Journal of Medieval Studies, 56*(4), 710-727.
- Yarzebski, J., Goldberg, R. J., Gore, J. M., & Alpert, J. S. (1994). Temporal trends and factors associated with extent of delay to hospital arrival in patients with acute myocardial infarction: the Worcester Heart Attack Study. *American Heart Journal, 128*(2), 255-263.
- Zerwic, J. J., Ryan, C. J., DeVon, H. A., & Drell, M. J. (2003). Treatment seeking for acute myocardial infarction symptoms: Differences in delay across sex and race. *Nursing Research, 52*(3), 159-167.

## GLOSSARY OF MAORI TERMS

Aotearoa	The Land of the Long White Cloud (Maori name for New Zealand)
Hapu	Sub tribe
He korowai oranga	The cloak of health (document outlining the health and disability policy for Maori)
Hinengaro	State of mind, mental health
Iwi	Tribe
Karakia	Blessing or Prayer
Kaumatua	Male elder
Korero	Talk or speech
Kuia	Female elder
Maemae	Pain or sore
Mahi I ra	Stressed out because of doing too much
Mana	Authority or leadership
Manaakitanga	Overall supporting love
Manuka	A tea tree (native flora of New Zealand)
Marae	Meeting ground
Maungapohatu	Name of a place or stronghold
Mokopunas	Grandchildren
Mo tau iwi	Stressed out because of tribal obligations
Nga tonu waa ka hua	How in its time it will come to fruition
Ngkau	Heart
Noa	Safe or profane
Pa	Fortified stronghold or village
Pataka	Storehouse
Puha	A sow thistle or green vegetable plant (when cooked as a vegetable it tastes similar to spinach)
Rahui	No trespassing or off limits in order to conserve resources, e.g. conserving supplies of shellfish
Rangimarie	Means peace within the heart
Rongoa	Maori medicine

Rua's stronghold	A Maori pa or fortress
Taha Maori	Maori dimension
Taihoa	Stop, soon or wait awhile
Tangata whenua	Local people
Taonga	Treasures
Tapu	Sacred, risky or not safe
Te Ao Tawwhito	Childbirth ritual
Te ao marama	World of light
Te po	World of darkness representing the womb
Te Kianga	Act of speaking
Te Reo Maori	Maori language
Te Whare Tapa Wha	A Maori health model - the title symbolises 'A Strong House'
Te Ao Tawwhito	Customary way of dealing with pain in childbirth
Te aroha	Refers to the heart as a symbol of love and caring
Te Kianga	Category of love - it is the practising of values to get things right
Tiki toku rata	Fetches my doctor
Tinana	Physical or body
Tohi	Ritual whereby a new baby is washed after the birth
Tohu	Sign of bodily sensations, a symptom or tribal landmark or signal
Tohu iho	The name for burning fires that indicate where a Maori chief's boundaries lie
Tohunga	Medical expert in Maori medicine, priest
Tokotoko	Carved walking stick
Ururewas	Mountain range in the North Island of New Zealand
Wai	Water used in spiritual and symptomatic ways for traditional healing
Wairua	Feelings or Spirituality or spiritual dimension of the heart
Whakatane	Name of a town
Whakama	Ashamed
Whakamomori	Humiliation or to grieve deeply
Whakapapa	Ancestral lineage
Whakmaemae	Inflict pain or the pain associated with childbirth

Whakawhanau	Giving birth, producing the family or a child
Whanau	Extended family
Whare kohanga	Sacred practices surrounding childbirth in Maori society, a separate house away from the village, a place to give birth
Whare tangata	Literally means a house for a person, a pregnant woman's abdomen
Whenua	Land or earth