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Māori Women, Health Care, and Contemporary Realities: A Critical Reflection

A thesis presented in partial fulfillment of the requirements
for the degree of Doctor of Philosophy (Health)
at Massey University, Wellington, New Zealand.

Beverley May Parton

2015

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Abstract

Māori women, health care and contemporary realities is a critical reflection on the context of my nursing practice, a Pākehā nurse employed by Kokiri Marae Health and Social Services (KMSS), Lower Hutt, Aotearoa New Zealand. In addressing the disparities Māori experience KMSS has the motto, “Committed to the holistic development of whānau, hapū, and iwi”. The research aimed to explore from the experiences of urban Māori women, influences on their health and health care engagement. Kawa Whakaruruhau, the critical nursing theory of cultural safety for Māori health care, informs a qualitative approach, a human rights perspective, with its categories of difference, power, and subjective assessment. In turn, whiteness theory, with its categories of white (and not so white) power and privilege, informs Kawa Whakaruruhau. The women’s stories were received in an unstructured interview method and analysed thematically. The historical, social, cultural, economic, political, racial and gendered factors contributing to Māori women’s health and health care engagement are presented as a geography of health, and as landscapes past, present and future. Landscapes past tell of the disruption of the whakapapa connections of land, language and health by the historical and ongoing processes of colonisation. Landscapes present tell of health care places and spaces that by their policies, cultures, structures, and health professional practice, network and connect to include or to exclude Māori women and their families. Landscapes future are envisioned by the women as they remember what is and has been, and then imagine for themselves and at times succeeding generations, what they require as Indigenous to be central to health care. The women imagine what they need to parent for their children to have a good life; they imagine a therapeutic landscape. (In)authentic identities are presented as chronicities of risk, inhabiting disease and poverty. The women expressed authentic mana wāhine identity uniquely and heterogeneously. Recommendations have been made for nursing practice, research site and research.

Acknowledgements

While the thesis expedition is relatively solitary, life of necessity is not, thankfully. Support of various kinds in the expeditions planning, undertaking and completion is mine to gratefully acknowledge.

Firstly, thank you to Kokiri Marae Health and Social Services (KMHSS), and to Kokiri Marae for your embrace of me, and to Teresea Olsen as KMHSS general manager for the broad opportunities I have had in being whānau there. I wish to acknowledge the trust I was given to not only be employed as a nurse, but then to take an issue of our combined practice to research to doctoral level. That is something quite different. My team colleagues were trustworthy in our work together and in this research process. I learnt much from them formally in our team hui and informally in our conversations, home visits, and clinic work together. I appreciated their comments, questions, and assistance in research planning, advertising, recruiting and reviewing processes. Their discretion ensured I never felt the process was compromised. Thank you to those who read various sections in their support of this study, and particularly, I record my gratitude to Cheryl Davies, manager of Tu Kotahi Māori Asthma. To Sharon Reid, my line manager and study organisation supervisor, I acknowledge my debt in my approach to the research through our discussions, and Sharon's challenges, insights and support. The insight I most attribute to Sharon is to remember the risk that someone may take what in good intent I have written and use it to further colonise Māori women.

I acknowledge those of my colleagues at Kokiri Marae Health and Social Services who have lost loved ones during the time I have been writing this thesis. I learned something of what it means to be part of a Māori community and that has informed my writing. Losses happen in all communities, to all families, to each of us, expected and unexpected. That is life and we are all mortals. With whānau it is the ages, and often preventable nature of deaths, the burdens of loss that (so wrongly!) appear part of being Māori in Aotearoa New Zealand today. So, too, is the tangi, and the courage I have known in my colleagues to continue to work for the time when Māori health will be as good as, or better than, the health of any other population group in Aotearoa as promised in Te Tiriti o Waitangi.

I have been privileged to experience at Massey University, Wellington, the expertise, knowledge, encouragement, humour, and patience of my supervisors, Professor Annette Huntington, principle supervisor, and Associate Professor Jean Gilmour, with Dr Lis Ellison-Loschman's expert contribution at significant stages. Professor Denise Wilson was an external advisor (Māori) earlier in the project, and also contributed significantly to my previous

postgraduate nursing learning, as did Professor Jenny Carryer, Dr Suzanne Phibbs, and Dr Jill Wilkinson. Ngā mihi nui.

As a distance student, I salute Massey University Library and its Distance Service for its systems, resources, and helpful, pleasant, and expert staff. The thump heralding the delivery of a red and yellow parcel at my back door has been a privileged part of my life for a number of years of university study, so I record my gratitude to the courier service.

I respectfully acknowledge the receipt of ethics approval from the Health and Disability Central Regional Ethics Committee for the initial study and for its doctoral level extension (Appendix 1 & 2).

Over the years of postgraduate study I have been encouraged with my study by the following grants and awards:

2007 New Zealand Federation of Graduate Women Manawatu Branch

2008 Hauora Māori, Ministry of Health

2009 Hauora Māori, Ministry of Health

Massey University Graduate Nurses' Fund

Nursing Development Unit, Hutt Valley District Health Board (for New Zealand Nurses Organisation Nurses Research Conference presentation)

2010 New Zealand Nurses Organisation NERF (Greta & Harry Hamblin Trust Research)

2011 International Nurses Day Excellence Awards, Hutt Valley District Health Board

2011/12 Kokiri Marae Health & Social Services

2012 Wellington Nurses' Education Trust Grant, New Zealand Nurses Organisation

2013 Manu Tipuranga Scholarship, Hutt Valley District Health Board.

I acknowledge good friends who have supported us in my journey. I especially pay tribute to dear long-time friends, confidantes, and mentors, Alison and Roger Crawshaw. It mattered to me deeply when telling Alison of the possibility of this project that Alison animatedly encouraged: 'Go on, do it'. They have both, sadly, passed on before its completion.

I acknowledge the gift from my parents, Esther and (the late) Robert Mossop, of early friendships with Māori in the Central King Country whom I knew as aunts and uncles; and much more. The significance of experiencing nurture by Māori in my early formative years informs my very essence, my life perspectives and ideals of a just and fair society for Māori and Tāiwi in Aotearoa New Zealand. Anything else makes no sense. I salute the whānau and the

memory of the ‘aunties’ about whom I begin this project, and the positive relationships of that time and place.

Family life and university study have cohabitated for years shaping each other. To Benjamin, Chloe, Abigail and Keturah, I have benefited richly from your love and support in my life. Your communications via various modes from both near and far and diverse places have connected our worlds of ideas and notions of justice and kept our hearts listening and talking. Sharing academic journeys across the Tasman has been an unanticipated bounty, Chloe. Thank you Tim, I’ve appreciated your calm technical assistance. To John Parton with whom I have lovingly shared more years than not, thank you for your unwavering love and care, encouragement, and support. You never doubted.

I offer deep gratitude to Angel, Ani, Anne, Aroha, Dolores, Fran, H, Louise, Makere, Marie, Mary, Pam, Patricia, Shar, and Tairua (self-chosen participant names) for your trust and support with my learning. I will always be grateful to you as wāhine Māori for gifting me stories that were both your own experiences and knowledges, and those of precious whānau. I hold your taonga with the utmost respect. You gave me so much more than I could ever present. My hope is that together we have produced something to encourage the good and to promote change where disadvantage for Māori women and their whānau persist. Ngā mihi nui ki a koutou.

Finally, from my heart and with love, I remember Yvonne.

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Chapter One: Introduction

*“There are in our existence spots of time
Which with distinct preeminence retain
A fructifying virtue. ”*

“Spots of Time” (Wordsworth, 1799/1987, p. 25)

“There are spots of time, inconsiderable remarks, chance encounters, days which at the moment seemed like any other day, but which, seen in the light of all that was to be, became extraordinarily important.” (Blaiklock, 1981, p. 73)

‘Spots of time’

Disparities between Māori and Tauīwi¹ in my homeland of Aotearoa New Zealand have oscillated background/foreground my whole life, leading in time to this enquiry focused on the health disparities experienced by Māori women and their whānau. I begin with the metaphor ‘spots of time’, and reflections from my childhood and nursing practice contextualising my purpose in researching the health and health care engagement of Māori women. Next I outline the conventions I use, background the study by overviewing Māori and Tauīwi historical arrivals and the bicultural foundation of Aotearoa New Zealand, followed by the traditional organisation of Māori life to locate the place of Māori women. Disparities between Māori and Tauīwi are briefly foregrounded against health being argued as a basic human right. The research site of Kokiri Marae Health and Social Services (KMHSS), Lower Hutt, and its affiliates, are positioned historically, providing a unique setting supporting and enabling recruitment, with cultural guidance, for this study. The chosen methodology is qualitative informed by critical theory, in particular, the Aotearoa New Zealand nursing theory of Kawa Whakaruruhau/cultural safety for Māori health. The study is presented as a critical geography, a whakapapa of health. The final section of *Chapter One: Introduction* is an overview of the logical linking of the following chapters to achieve the aim of the enquiry. I begin with ‘spots of time’ from my childhood and nursing practice.

The first woman’s story I never heard. Our small mill town neighbour, a girlfriend’s mother, ‘Aunty’ as we knew her, and now in the closed casket in the wharenuī, the ancestral meeting house. We were barely in our teens. The ‘spots of time’ were blankets under our chins when

¹ Māori are the Indigenous Peoples of Aotearoa New Zealand, while Tauīwi are all other Peoples. See *Thesis conventions* (p. 3) for a fuller explanation.

the adults went for kai (food), my sister one side and I the other of our bewildered friend as we lay on one of the customary mattresses made into beds on the meeting house floor. The funeral day and the talking, my dad waiting for his turn; a small utility vehicle with casket and possessions leading the procession to the urupā (family cemetery) way out the back on whānau land.

The second woman's story I ponder, too, from the same whānau in my home place. I saw her, unexpectedly, sitting with her younger ones, the same soft frame of black curls around the dark eyes and warm and ready smile I'd known and responded to as a child. (I still have two children's books she had given me before they'd moved to whānau land not far but a long way.) I was a newly registered nurse (RN), and recently, and briefly, had returned from the city to work at the local rural hospital. She was in Outpatients waiting for a visiting specialist for her children. A widow after a work accident, she, too, passed within a few years leaving their large family orphaned. A delightful happenstance that day, a spot of time I contemplate, sadly, and my questions from then resonate with experiences from my nursing practice as it has come to be.

Living as a Pākehā child in a Pākehā/Māori rural village dependent on the timber and farming industries gave me opportunity for rich relationships and, on reflection, beginning knowledge by secondary school of difference in educational and health outcomes for Māori. The Māori renaissance gathered momentum throughout my nursing career, which saw the Māori-driven development of Māori health providers (Durie, 1998), and the development of cultural safety theory in nursing, named by Māori as "Kawa Whakaruruhau" for Māori health and for all recipients of health care (Ramsden, 2002, p. 2). At the beginning of the 21st century *The New Zealand health strategy* (A. King, 2000), *He korowai oranga: Māori health strategy* (A. King & Turia, 2002) and *The primary health care strategy* (A. King, 2001) were implemented nationally, which provided opportunities for nursing in primary health. Within that setting, at the beginning of 2003, I was employed as a registered nurse at KMHSS, Lower Hutt.

As a nurse in a Māori health provider, I heard stories from Māori women that were distinct and preminent in their inner beings, stories giving voice to their experiences of health and wellbeing and health care and resistances. Sometimes the impact of whānau experiences meant a woman attended to her health and health checks promptly. Other times there was the telling of enduring embarrassment, inconvenience and discomfort thinking they were on a waiting list for interventions they were not. Or of becoming hapū waiting for a sterilisation appointment not received. Or of feeling violated undergoing a procedure where no one in the preparation, consent, intervention or post-intervention processes considered tikanga, causing spiritual dissonance that affected recovery. Or of health checks years before that impacted the woman to

the degree a repeat procedure was not wanted, resisted. Or of a woman attending to her own health needs and priorities of whānau and hapū over an appointment scheduled, such as when fulfilling the important role of kaikaranga for tangihanga. The stories suggested unique and intersecting processes largely hidden, that I suspected could contribute to the documented disparities in health between Māori and Tauīwi women (Talamaivao et al., 2010). Before developing the purpose of this enquiry further, I will outline conventions I have used.

Thesis conventions

I use ‘Tauīwi’ in preference to ‘Pākehā’ or ‘non-Māori’, except where non-Māori and Pākehā are referenced and in describing myself, as I have always considered myself ‘Pākehā’, usually understood as a “New Zealander of European descent” (Moorfield, n.d.-d). ‘Tauīwi’ means “...foreign people, non-Māori, foreigners, immigrants” (Moorfield, n.d.-e) while the meanings of ‘Māori’ include “...normal, usual, natural, common.... indigenous, ...belonging to Aotearoa/New Zealand...” (Moorfield, n.d.-c), a new collective identity for the Indigenous Peoples of Aotearoa New Zealand that came with European colonisation (Royal, 2013b). The first official document in which ‘maori’ was used was Te Tiriti o Waitangi (1840) in the third article (Walker, 1990). ‘Tauīwi’ allows for the variety of descent, (for example, European, Asian, African) of Aotearoa New Zealanders who were not Māori in the women’s stories, without the sense of negation I feel that ‘non’ as a personal descriptor gives in the usage of ‘non-Māori’. The capitalisation of Tauīwi and Indigenous in this study, except where they are in quotations, is my acknowledgement of Indigenous and Tauīwi as proper names of distinct people categories in Aotearoa New Zealand. I use the term ‘health care engagement’ as potentially more neutral than terms in the literature such as compliance, adherence and concordance (Bissonnette, 2008; Cohen, 2009; Snowden, Martin, Mathers, & Donnell, 2014). I critique these terms in *Chapter Two: Literature Review*.

Te Reo Māori, English, and New Zealand Sign Language are the official languages of Aotearoa New Zealand and I have left Te Reo Māori and English to stand together in the text without italisation. Except where I am emphasising meaning in the text, I leave the translation of Māori words to the *Glossary* at the end of the work. Māori is traditionally an oral language. Macrons as horizontal lines are used in written Māori over vowels to show it is a long vowel, a convention I follow except where the quote, reference, or name does not (Māori Language Commission, 2012). Some quotations are from an era previous to the macron convention being formalised, so a double vowel may have been used in the written form, or no indication given in written form, for example, Maaori or Maori. I use ‘Aotearoa New Zealand’ without a forward slash separating the names, although ‘New Zealand’ is still the official name, as I feel it reflects the bicultural nature of our country and is aspirational. In the telling of the stories above and

elsewhere I have used Māori words with English, often a conversation convention when with colleagues at the marae as it was with participating women. Irihapeti Ramsden (2002) has capitalised the first letters of ‘Cultural Safety’ and ‘Kawa Whakaruruhau’. I use ‘cultural safety’ unless in quotations, but I have kept ‘Kawa Whakaruruhau’. Having clarified my writing conventions, I’ll return to the study field by briefly backgrounding the beginnings of Aotearoa New Zealand, and the organisation of Māori life to position the Māori women in their historical and social context.

Background

Māori and European explorers and bicultural beginnings

Māori are of Polynesian descent and are the Indigenous Peoples of Aotearoa New Zealand arriving and returning on different ocean-faring waka from and to East Polynesia during the thirteenth century (Royal, 2013a). Their exact place of origin, the ancestral Hawaiki, is contested. ‘Aotearoa’ (long white cloud), the Māori name for New Zealand, was credited to an early ancestress, Kuramārōtini, whose husband was Kupe, the acknowledged discoverer of Aotearoa New Zealand (Barclay-Kerr, 2012). In time, Māori explorers landed waka in various places, eventually exploring throughout the whole country. Landing and settlement sites are important genealogical places for iwi, hapū, and whānau whakapapa connections, connections that will be explained below. Dutch explorer, Abel Tasman sailed to, and named, ‘New Zealand’ in 1642 but he did not land (Royal, 2013a). English explorer James Cook first landed in 1769 and European colonial settlement began in Aotearoa New Zealand at the beginning of the nineteenth century.

The bicultural foundation of Aotearoa New Zealand is The Treaty of Waitangi/Te Tiriti o Waitangi (Te Tiriti), a covenant between Māori and British Government representatives of Queen Victoria (The Crown), that was first signed at the Bay of Islands in 1840 and then by other Māori leaders through the country (Waitangi Tribunal, 2013b). Hāpu, in effect, gave the Crown the right to govern and in reality Te Tiriti is between Māori and everyone else who comes to Aotearoa New Zealand. There are two texts, English and Māori, which have been problematic as the translations differ at certain points. When taking into consideration Māori understanding at the time, other Crown documents, Te Tiriti’s Preamble, Three Articles and the Epilogue, both versions may be seen to “... represent an agreement in which Māori gave the Crown rights to govern and to develop British settlement, while the Crown guaranteed Māori full protection of their interests and status, and full citizenship rights” (Waitangi Tribunal, 2013a, p. 1). It has been argued that equality inherent in full citizenship rights as promised in Te Tiriti is not demonstrated in the disparities in health experienced by Māori (Mikaere, 2011).

Health disparities with particular reference to Māori women will be outlined, but first the organisation of Māori life and the centrality of whakapapa is briefly described.

Whakapapa and the organisation of Māori social life

Whakapapa is a conceptual foundation of Māori thought (Mikaere, 2011) that as a metaphor of connections is considered in *Chapter Three: Mapping the theoretical terrain*. At the level of Māori social life whakapapa refers to kinship connections through descent organised into four groups recognised through naming: whānau, hapū, iwi, waka (Ministry of Justice, 2001).

Family descent may be equally through either parent or both, that is, they are ambilineal².

Whānau, meaning, “to be born, to give birth ... [and] ...family, family group” (Moorfield, n.d.-g) is the basic intergenerational and whakapapa unit into which a person is born (Ministry of Justice, 2001). In traditional times the whānau lived together and carried out the personal, social and economic support of everyday living guided by koro/koroua/pōua and kuia/taua³, the grandfather and grandmother⁴. The kin responsibility, reciprocity, and close relationship are

² In general, Māori society is described as being democratic, and as having three main classes:

Rangatira (chiefs), tūtūā or ware (commoner), and taurekareka (slaves captured from other tribes). Tohunga (priestly experts) were also sometimes included as a separate grouping.... Rangatira status was determined by birth. The first-born of the most senior family in an iwi was ariki. (Keane, 2013, p. 1)

Although of different status, genealogical descent could be claimed to a common ancestor. Through intermarriage with free individuals slavery was not lineal, though it may mean the offspring would be considered of a lower class. Special feats could give more status than birth order as was claimed by the atua, Tūmataunga, “the god of man and war”(Keane, 2013, p. 2). Generally, women could be ariki and either the woman or her husband would carry out the functions of ariki. In the Ngāti Porou iwi, primogeniture may be equally female or male, as evidenced in senior leaders claiming descent from powerful women leaders in their whakapapa, the number of stories of women of high birth status exercising the rights and responsibilities of leadership, women maintaining status even in marriage, women leaders’ speaking rights and the respect given to them on marae, women as composers of song and even haka (Mahuika, 1973). The only area in which women did not usually exercise leadership was in war. Ngāti Porou women’s mana may be seen in the number of meeting-houses named after an ancestress (Mahuika, 1973; Simmons, 2006). Mahuika (1973) concludes that in Ngāti Porou it was primogeniture and leadership ability and not gender that determined who should lead. This should not be generalised to other iwi.

³ These were the different dialectical terms for grandfather and grandmother used by the women in their interviews.

⁴ The grandparents and their generation, such as grand uncles and aunts, carried out tasks for the survival of the whānau and played important roles as repositories of knowledge, child carers and educators, and whānau spokespeople (Ministry of Justice, 2001). Membership of the whānau of the other parent was equally fostered as kinship lines were recited in genealogies, and kin relationships kept current by providing reciprocal support when required. Whānau groupings could comprise between three and six generations, size often being delineated by space (Mahuika, 1973).

referred to as whanaungatanga. The concept of whānau, and whanaungatanga, in modern times also extends to groups that do not have familial ties. For example, I am considered, and I consider myself, part of the Kokiri Marae whānau. When home visiting whānau with a community health worker in my nursing practice, the greeting included whakawhanaungatanga, the process of making connections with the people we were visiting.

A hapū comprises a cluster of kin-related whānau who worked together as a political unit led by a rangatira to maintain alliances for the protection of land and resources (Ministry of Justice, 2001)⁵. Another sense of the word “...be pregnant, conceived in the womb” (Moorfield, n.d.-a) reinforces the kin-based notion of hapū. Similarly, iwi has the meaning of “strength, bone” (Moorfield, n.d.-b) and an iwi is a federation of hapū led by an ariki (Ministry of Justice, 2001). Politically and economically, an iwi is the strongest entity of Māori social life, demonstrating shared descent from the bones of a common ancestor and shared connection to whenua, maunga, awa or moana of the iwi ancestor. Shared descent is integral to the concept of whakapapa, where each person is a member of a whānau, each whānau is part of a hapū and in turn an iwi, and each iwi aligns with a particular waka and ancestral leader who migrated to Aotearoa New Zealand eventually claiming a particular place. The reciting of genealogy and the telling of stories connects through whānau, hapū, iwi, and waka to Hawaiki and to the creation of all things and human kind (Walker, 1992). Hence in whakapapa, Māori consider themselves connected to all things in creation, a concept that will be further discussed in *Chapter Three: Mapping the theoretical terrain*. Another aspect of the study landscape is the statistical description of the Aotearoa New Zealand population with a focus on Māori women.

Population

The total Aotearoa New Zealand population on March 5, 2013 was 4, 242, 048, of whom 14.9 percent identified as Māori (598,605) (Statistics New Zealand, 2013a). In the December 2010 year 74 percent of all babies born belonged to only one ethnic group, while 69 percent of Māori babies belonged to two or more ethnic groups (Statistics New Zealand, 2011). Overall, one out of four babies born in 2010 and one out of seven mothers belonged to more than one ethnic group demonstrating an increasing trend to belonging to more than one ethnicity in Aotearoa New Zealand. Though Māori are a minority population in their own country, the Māori population is growing at a faster rate than Tauīwi. In 2010 the overall total fertility rate in Aotearoa New Zealand was 2.2 births per woman and for Māori 2.8 births per woman. The internationally recognised replacement rate is 2.1 births per woman. The median age for Māori mothers in 2010 was 26 years and for the total population 30 years. In the same year the overall highest fertility rate was for women 30-34 years (126, births per 1,000 women) and the highest

⁵ Hapū as a social unit may take six to ten generations to develop (Mahuika, 1973).

Māori fertility rate was for women 20-24 years (156 births per 1,000 women). In 2009, the under 20 years (15-19 years females) fertility rate was 29.6 births per 1000 for all ethnicities, 71.6 per 1,000 for Māori (15-19 years females) and 18.4 per 1000 for non-Māori (15-19 years females) (Ministry of Social Development, 2010). More Māori women give birth at a younger age than Tauwiwi women, which has service access and appropriateness implications in this study. Against this picture of a growing Māori population, Māori women experience health disparities.

Health disparities between Māori and Tauwiwi

Highlighting health disparities between Māori and Tauwiwi that are relevant to this study is to place the disparities in a Te Tiriti framework where Māori are promised health equal to or better than that of any other Peoples (Ministry of Health, 2013b; Reid, Robson, & Jones, 2000).

Rather than sensationalising victim blaming, a Te Tiriti position takes a broad contextual view to assess and address societal structures and systems of injustice, allowing for Māori resilience and visioning. Other theoretical and methodological aspects will be introduced below but first, selected health disparities for Māori women will be added to the landscape vista beginning with the overview of life expectancy at birth. For Māori females in the period 2010-2012, life expectancy at birth was 76.5 years compared with 83.7 years for non-Māori females, a gap of 7.3 years (Statistics New Zealand, 2013c). This disparity has improved from the 1995-1997 period when the gap was 9.3 years. Life expectancy from birth and higher Māori fertility rates are reflected in the median age of Māori females being 24.2 years (20.8 years in 1992) compared to 38.2 years for non-Māori females (Statistics New Zealand, 2013b). In the *New Zealand Burden of Diseases, Injuries and Risk Factors Study, 2006–2016* (Ministry of Health, 2013b), Māori were found to experience loss of health at a rate 1.8 times higher than that of non-Māori, and over half of the loss of health for Māori occurred prior to middle age. The leading conditions contributing to absolute Māori non-Māori health loss inequalities were: “coronary heart disease, diabetes, lung cancer and COPD⁶” (Ministry of Health, 2013b). Further selected health disparities relevant to this enquiry are discussed in *Chapter Two: Literature Review*.

Socioeconomic disparities between Māori and Tauwiwi

Socioeconomic disparities affecting Māori health are demonstrated in income, house crowding, education, employment and prison numbers (Perry, 2009; 2013; Ministry of Education, 2013; Department of Labour, 2012; Statistics New Zealand, 2013d). As women are the main carers in families, Māori women are disproportionately caring for families with insufficient income to meet basic living needs such as food, health care, communication, clothing, support for education and extracurricular activities, and transport. The Ministry of Social Development’s

⁶ COPD - chronic obstructive pulmonary disease

2008 Living Standards Survey found that 39 per cent of Māori children⁷ aged 0-17 years lived in households where economising measures such as limiting fresh fruit and vegetables, delaying medical care, and household crowding were used (Perry, 2009). The 2011-12 Household Economic Survey reported that 21 per cent of children in Aotearoa New Zealand are living in poverty⁸ and that 50 per cent of children living in poverty are Māori or Pacific (Perry, 2013).

The New Zealand Health Survey 2011/2012 found that Māori have a higher level of self-reported unmet health need than other people, with cost of health care being a major determining factor (Ministry of Health, 2013a). Māori and Pacific have more admissions to hospital for close contact infectious disease than other Aotearoa New Zealand population groups where 28 per cent of Māori children and 45 per cent of Pacific children compared to 8 per cent of European/Other children are exposed to household crowding (Baker, McDonald, Zhang, & Howden-Chapman, 2013). Infectious disease admissions to hospital were greatest for those in the areas of highest deprivation categories with Māori and Pacific disparities having increased during the previous 20 years (Baker et al., 2012). Social and economic policies and their implementation produce inequitable rates of poverty, which have been found to contribute to a range of poor health outcomes (Tobias, Blakely, Matheson, Rasanathan, & Atkinson, 2009), and are associated with higher rates of childhood abuse (Wynd, 2013).

In 2012 48.6 per cent of the total Māori and Tauīwi school leavers, compared to 26.7 per cent of Māori school leavers, left school with a university entrance qualification considered the requirement for further tertiary study or the entry level for many jobs (Ministry of Education, 2013). Where schools draw students from areas of highest socioeconomic disadvantage, 21 per cent of Māori school leavers left with a university entrance qualification, the lowest of any ethnicity. In comparison, 60 per cent of Māori school leavers from schools drawing from quintile one areas, the areas of most advantage, left with a university qualification, demonstrating the effects of socioeconomic status on educational achievement.

Unemployment is an indicator of disadvantage and the Māori unemployment rate for the year to March 2012 was 13.3 per cent compared to 6.6 per cent for the total population (Department of Labour, 2012). The rate for NEET (Not in Education, Employment or Training) which measures youth (15-24 years) disengagement for the year to March 2012 was 17.6 per cent for Māori males and 11.5 per cent for the total male population, 27.5 per cent for Māori females and 14.6 per cent for the total female population. The NEET Māori female rate is likely

⁷ Pacific children 51 per cent, 'Other' children 23 per cent, European children 15 per cent

⁸ After Housing Cost (AHC) fixed line measure

influenced by the high Māori fertility rates for that age group as noted above. In June 2012, 58 per cent (n=304) of women prisoners and 51 per cent (n = 4087) of male prisoners were Māori, indicating a disproportionate burden of care in the Māori population for incarcerated whānau and their dependents (Statistics New Zealand, 2013d).

The detailed linking of various demographic statistics is outside the scope of this study. However, the combined socioeconomic disadvantage perpetuating disparities in qualifications on school leaving, youth engagement in work, training and education, employment and imprisonment, give a picture of a socioeconomic and political landscape of structural inequities that are important determinants of health.

Health as a human right

The disparity in health between Māori and Tauīwi women in Aotearoa New Zealand is a social injustice, a human rights issue (Reid & Robson, 2007). Globally, health as a human right has been established by member nations of the United Nations (1948, 1966/1976) and the World Health Organisation (2011, 2012, 2013a), and in particular for this study, as a right of Indigenous Peoples (United Nations, 2008). Human rights concern the “inherent dignity and ... the equal and inalienable rights” of each human being and are “the foundation of freedom, justice and peace in the world” (United Nations, 1948, para 1). Achieving the human right to health is dependent on social determinants of health defined as:

The circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics. (World Health Organisation, 2013, para 4)

Inequality in health is about difference and inequity about unfairness (World Health Organisation, 2013a). Not all inequalities or differences between individuals can be eliminated, but avoidable health disparities or differences due to unfair systemic structures in society and unfair conditions of everyday life are inequitable. The social determinants of health comprise the social, economic, and political structures in society; peoples’ everyday communities where they live, work or access leisure; and peoples’ access to healthy housing, education, health care, and the goods of society. Globally, the poorest countries and the poorest within countries, such as the poorest within Aotearoa New Zealand, have the worst health. Conversely, good health is enjoyed by those most socioeconomically advantaged. The social determinants of health across all socioeconomic levels are reflected in a gradient of health that is in turn affected by and impacts access, appropriateness, affordability, timeliness, and quality of health care. A human

rights discourse in health concerns fairness for all in society based on respect for human dignity that enables individuals and groups to attain their potential.

A marginalisation discourse exists where groups are seen as vulnerable, 'hard to reach', marginalised. This representation could be perceived as a binary to invincible, impervious, accessible, centre, mainstream. Labeling a group as marginal may be critiqued as othering from positions of power, and different forms of marginalisation have been described (Hurley, 2007). It is possible that the experience of inaccessible health care for whatever reason may be experienced as feeling marginalised. I argue in *Chapter Three: Mapping the theoretical terrain* that the margins with resistance may become places of power, of change. There has been a level of political change over the past three and a half decades in response to Māori leadership and Māori resistances that has been recognised by government in policy changes, and the development of 'by Māori for Māori' services to address Māori health inequities. The Māori health provider based within an urban marae that has been my work place and subsequently became the research site is KMHSS, which I will introduce with a description of marae generally.

Research site: Kokiri Marae Health and Social Services

A marae is a peculiarly Māori institution where Māori may be Māori (Rangihau, 1975). It is a place for Te Reo Māori me Ngā Tikanga Māori to be nurtured and to nurture; it provides a tūrangawaewae, a place to stand, a connecting space, a sacred space. Marae were traditionally on whānau land, which for most were rural until the 1960s when urban marae began to be built to meet the needs of Māori who had migrated to the cities (Meredith, 2012). A marae-based Māori health provider is a space for Māori knowledges to inform ways of being and it creates contested spaces for Māori and Indigenous worlds to link with other knowledges and new and expanding knowledges in reciprocity and partnership. As a contested space it is where The Crown, represented by various funders, manuhiri with power and difference, purchase services. In the purchasing of services, Māori health providers, it has been found, are inequitably treated by The Crown (Came, 2012). In comparison to other providers, Māori health providers have shorter lengths of contracts, more frequent auditing and monitoring, and lesser funding access, which all contribute to difficulties in planning, in meeting need.

KMHSS is an urban Māori health and social services provider based at Kokiri Marae. Similarly to a number of other Māori health providers in Aotearoa New Zealand, KMHSS provides health and social services outside and independent of general practitioner services. Kokiri Marae developed out of the Tu Tangata ('to stand tall') government policy reforms of the 1980s

(Kokiri Marae, n.d.-a)⁹. Government policy governing the relationship of The Crown to Māori has been argued as having been assimilationist and protectionist from the time of Te Tiriti in 1840, to those reforms (Fleras, 1985). Fleras (1985) cited factors such as the 1970s Māori renaissance, government concern at burgeoning welfare costs, and the failure of paternalistic and top-down policies to address disparities between Māori and Tauīwi, as contributing to government recognition of the need for change. The Tu Tangata policy signaled a government change to a community development, grassroots approach that valued the resources and strengths of Māori to meet Māori need in a culturally appropriate way.

‘Kōkiri’ means ‘to advance’ and with the passing of new legislation in the Maori Affairs Act ("464A Authorising establishment and maintenance of Kokiri Centres," 1953 & Supp.1980) the first Kokiri Centre of the Tu Tangata initiatives was established as an employment training scheme in an ex-USA 1960s Army store at Seaview, near the Hutt River mouth in Wellington Harbour (Fleras, 1985; Kokiri Marae, n.d.-a). With the seeding of community initiatives under the leadership of Keriana Olsen, the inaugural Kokiri Centre developed into an urban marae contributing to local and national policy direction in Māori education, providing health and social services, promoting the revival of Te Reo Māori language and other cultural practices. The whānau support available on site formally became Kokiri Marae Health and Social Services (KMHSS), which with Kokiri Marae Te Kōhanga Reo and education and employment services, is still based at the community facility. The motto is “Committed to the holistic development of whānau, hapū, and iwi.” The kaupapa is to be open to whoever has need.

While some initiatives have become separate entities, such as Te Ara Whanui Kura Kaupapa Māori (Māori-medium primary school, years 0-8), other initiatives have remained as affiliates under the overall management of KMHSS. It is in KMHSS and affiliates and the marae community that nursing has provided a resource across all programmes and for all personnel. In particular, KMHSS programmes and contracts involving nurses as identified in the women’s stories, were various whānau ora contracts providing a range of nursing interventions; an outreach immunisation service for Māori, Pacific and other high needs groups; a predominantly population health programme for sexual and reproductive health; and nursing practice within the Kokiri Marae affiliates Mana Wahine and Tu Kotahi Māori Asthma¹⁰. For the women and

⁸ Tu Tangata was initially led by a Lower Hutt Te Āti Awa leader, Ihakara (Kara) Puketapu, who as then Secretary of the Department of Maori Affairs, was directly responsible to its minister (Fleras, 1985).

¹⁰ Tu Kotahi Māori Asthma Trust (TKMA) was formed in 1995 to address Māori concern about the disparity in the incidence and management of asthma for Māori in the Wellington region (Kokiri Marae, n.d.-e). TKMA now delivers regional services for Māori providing advocacy,

their whānau, engagement with one health or social service, such as early intervention services and mothers' group¹¹, social workers, counselors or quit coaches (Aukati Kai Paipa)¹², Kokiri Marae Māori Women's Refuge¹³, or the marae educational services, potentially enabled engagement with other services within the marae community and beyond. As the health and health care engagement of Māori women is the focus of this study, I will outline the context and development of Mana Wahine Inc. as a service to explain how and why Mana Wahine sits within Māori health providers such as KMHSS in the lower North Island.

Mana Wahine

Mana wahine/wāhine refers to the prestige, honour, standing, reputation of [a] Māori woman/women. There are two main references to Mana Wahine in this study. One is to Mana Wahine research as a Kaupapa Māori, critical theoretical and methodological approach employed by Māori women scholars for studies focusing on Māori women and the intersect of ethnicity and gender (Pihama, 2001; Simmonds, 2011). The second refers to the Mana Wahine cooperative of Māori health providers in the contractual programme within which I provided registered nursing services as a nurse employed by KMHSS (Kokiri Marae, n.d.-c). Both Mana Wahine entities are capitalised as proper nouns but it is the context of the second, Mana Wahine Inc. that I will describe here.

support, education and resources for both personal and population health for asthma and other respiratory diseases, for example, COPD and bronchiolitis. It promotes healthy environments such as healthy housing, supports AKP and smoke free environments, and partners with researchers in respiratory and housing studies to benefit Māori.

¹¹ Nāku Ēnei Tamariki (NET), comprising Māori, Pacific, and Pākehā sections, formed in 1993 to provide culturally appropriate, early intervention, and home-based support for young parents and their children (Kokiri Marae, n.d.-d). NET Māori remains based at Kokiri Marae and through individual advocacy, support, education, and parenting programmes, encourage whānau to engage with well child healthcare and early childhood education.

¹² Aukati Kai Paipa (AKP) is a national Māori quit smoking programme that began in 1998 with pilots at KMHSS and six other sites (Aukati Kai Paipa, n.d.). Trained AKP coaches, now in thirty sites throughout Aotearoa New Zealand, provide ongoing kano ki te kano (face to face) and telephone contact support, and supply free, personally tailored nicotine replacement therapies. The population health component of AKP promotes Māori smoke free environments and life styles, education, resources, and local and national advocacy.

¹³ Kokiri Marae Māori Women's Refuge Incorporated (KMMWR), a member of the National Collective of Independent Women's Refuges Incorporated, was formed in 1998 to provide culturally appropriate care for families living in violence (Kokiri Marae, n.d.-b). KMMWR provides a 24-hour crises line staffed by volunteers, safe house accommodation, education services about family violence for affected women, anger management, and counseling and social support for both women and children.

Mana Wahine Incorporated operates as a network collective of six autonomous Māori health organisations within the Wellington and Wairarapa regions (Kokiri Marae, n.d.-c). The particular interests of Mana Wahine are with Māori women's health and engagements with the screening services and pathways of the National Cervical Screening Programme¹⁴ and Breast Screen Aotearoa¹⁵. KMHSS is a founding member of Mana Wahine and continues to play a key role. The beginning of Mana Wahine in 1990 was against the backdrop of significant developments both in inverting of government assistance for Māori as in the Tu Tangata policies and programmes as discussed above, and in women's health in Aotearoa New Zealand.

Mana Wahine Inc. and women's health in Aotearoa New Zealand

In the later 1980s women's health was highlighted after allegations about the treatment of cervical cancer at National Women's Hospital, Auckland. A ministerial inquiry was commissioned and the subsequent report released became known as *The Cartwright Report* (1988)¹⁶. Recommendations from *The Cartwright Report* (1988) included a centrally coordinated national cervical screening programme (pp. 201, 207-208); the choice of trained non-medical smear takers in clinics at various sites including marae (pp. 206-208); the establishment of a health commissioner and a code of patient's rights¹⁷; patient advocates (pp. 173, 214); consumer, women's health groups and Māori involvement in policy and programme direction and in evaluations (pp. 209, 217); and recommendations informing the nature of informed consent in treatment and research (pp. 136-137, 158-159, 167, 212). The Inquiry was informed about the sacredness for Māori of the genital tract (S. Cartwright, 1988, p. 115) and intimidated nurses at National Women's Hospital were censured for failing to openly advocate for the women (p. 172). The hierarchical medical domination of health care was challenged, Māori women's participation in services for Māori women at all levels legitimated¹⁸, and patient centred services were enshrined as best practice (S. Cartwright, 1988, pp. 129,

¹⁴ Available to all women 20-69 years of age (National Screening Unit, 2014b). All cervical smears are provided free to women by KMHSS.

¹⁵ The free national breast screening programme is available for women between 45 and 69 years of age (National Screening Unit, 2014a).

¹⁶ The full title of Dame Sylvia Cartwright's (1988) report is: *The report of the committee of inquiry into allegations concerning the treatment of cervical cancer at National Women's Hospital and into other related matters*.

¹⁷ The *Health and Disability Commissioner Act 1994* and *The Code of Health and Disability Services Consumers' Rights 1996* are in direct response to *The Cartwright Report* (1988) (Health & Disability Commissioner, 2009a; 2009b).

¹⁸ Māori women's participation includes *The National Kaitiaki Group* who are responsible to the Minister of Health to consider applications for Māori women's aggregate data from the National Cervical Screening Register (Ministry of Health, 2014e)

176). Concurrently with the national response to *The Cartwright Report* (1988) and the general concern for disparities between Māori and Tauīwi mentioned above, there were changes in the funding of services. Māori women's leadership was well placed to be part of progressing initiatives for Māori women.

Kaupapa Hauora Māori service

KMHSS in an urban marae base from and within which different health and social services have developed, is a Kaupapa Hauora Māori service. The difference for Māori between mainstream and Kaupapa Hauora Māori services is articulated in a study with kaumātua where a Kaupapa Hauora Māori service was seen as originating in Te Ao Māori with "the values, ideals and spiritual understanding that keep Māori well" (Wenn, 2007, p. 17). The fundamental values are "whakapapa, wairua, whenua, whānau, tikanga, te reo Māori, tinana, hinengaro" (Wenn, 2007, p. 150), which provide a measurable framework of ethical practice for quality auditing in a manner that makes sense to Māori. To accept the position of a nurse located in a Kaupapa Hauora Māori service is to accept its foundational values as Māori best practice; to accept the aspirations of Māori for health equal to or better than any other group in Aotearoa New Zealand; to acknowledge that no service exists in a vacuum, that all health care is a political and ethical endeavour and in the acknowledging of the socio-historical context of the effects of the interruption of colonisation on health status, Māori are equipped by way of redress to develop health services. It has been in a Kaupapa Hauora Māori provider that I've been supported to work and breathe and earn my living, not as manuhiri at all, but as marae whānau, as Tauīwi Pākehā, whangai even. In this context, the health and health care engagement of Māori women was foregrounded for me on a daily basis.

Research aim

It was the women's stories from my practice as a registered nurse at KMHSS that directly led to the formulating of this project. These stories gave a different light to the negative status women sometimes acquired when perceived by health professionals as not attending to their own health. The stories frequently had connection with the government policy of access, appropriateness and affordability for Māori (King, 2000). Some stories covertly demonstrated injustice, forms of oppression, by way of government policy not being met. Injustice in one form or another was often at the heart of topics discussed formally in hui or informally between our team members in our practice setting while the imperatives in our practice were embodied disparities and addressing barriers to health care. In journeys with women, I have experienced health care that could be complex, ignorant, and unfriendly, as exposed previously in literature (Wilson, 2004). I have also appreciated with women other services where there was a welcome, demonstrated competence and accommodating compassion. I have been perplexed when my own understanding of what the barrier could be for someone has been stretched and frustrated.

As a practice issue the context of Māori women's health and health care engagement became a focus and the aim was formulated:

In light of the health disparities of Māori women the aim of this research is to explore from the experiences of Māori women in an urban setting, influences on their health and health care engagement in Aotearoa New Zealand.

The aim guided the research process, as I continued to practise as a nurse amongst urban Māori women at KMHSS, learning from women with whom I am in community, and from the wider Māori, Pacific and other high needs communities in the Hutt Valley. The research is grounded in concrete and real issues occurring in historical moments of time as encountered with and by women and their whānau in my nursing practice and as such informs the social justice agenda of nursing. The study field is the context of Māori and Māori women in Aotearoa New Zealand and their health and health care engagement, disparities between Māori and Tauīwi, a Māori health provider and Mana Wahine Inc., and nursing practice in a marae setting. The methodological and theoretical approach I am taking is introduced next.

Methodology and theoretical perspectives

Qualitative methodology allows the women's experiences to be explored in depth (Gavin, 2008), and hui as method is an appropriate Māori forum for the passing on of information and for discussion (Bevan-Brown, 1998). The methodology draws on different theories to explore the influences on the health and health care engagement of urban Māori women. Critical theory enables the experiencing of everyday struggles to be interpreted in the light of the political, historical, socioeconomic, and cultural landscape and to be presented as a critical geography of health (Anthamatten & Hazen, 2011), a whakapapa. A geography of health has spaces and places, networks and connections (Eyles & Williams, 2008) and whakapapa is a concept central to Māori of relationships one to another and to all creation (Mikaere, 2011), and becomes both a metaphor and a physical reality within the critical theory and geography of health framework. The Aotearoa New Zealand nursing theory of cultural safety is a critical theory that has categories of difference and power and is subjectively assessed (Nursing Council of New Zealand, 2011; Ramsden, 2002). It has been a core part of the curriculum for the training of all registered nurses and midwives since 1992. Whiteness theory, as a critical theory, is argued as informing cultural safety in *Chapter Three: Mapping the theoretical terrain*, providing an analysis of the hegemonic power and privilege of being white at the pinnacle of the racial hierarchy that is a structure of society globally (Fine, 2004) and in Aotearoa New Zealand (Reid & Robson, 2007). Racial ideologies structure the intersection of gender ideologies and are implicated in social and economic policies oppressing Indigenous Peoples, and contributing to

the social determinants of health and health inequities. The background to Kawa Whakaruruhau/cultural safety will be outlined here.

Cultural safety/Kawa Whakaruruhau

Cultural safety/Kawa Whakaruruhau was named by Māori for a vision originally proposed for changes that needed to take place in nursing education and service that centred on the experiences of all recipients of nursing care (Ramsden, 2000, 2002). The Nursing Council of New Zealand (2011) now reserves Kawa Whakaruruhau for Māori health and Māori recipients of nursing care. Nurses as ‘other’ reflect on their attitudes, behaviours, culture and histories, to understand issues of power, and are then enabled to practise nursing in a way that the recipient of their care experiences it as culturally safe.

Cultural Safety ... is concerned with power and resources, including information, its distribution in societies and the outcomes of information management. Cultural Safety is deeply concerned with the effect of unequal resource distribution on nursing practice and patient wellbeing. Its primary concern is with the notion of the nurse as a bearer of his or her own culture and attitudes, and consciously or unconsciously exercised power. (Ramsden, 2002, p. 109)

Irihapeti Ramsden (2002) relates how at the Hui Waimanawa in 1988, a national gathering concerned with Māori nursing education, a student nurse of Te Arawa descent from Christchurch Polytechnic listened to others and then asked, “You people talk about legal safety, ethical safety, safety in clinical practice and a safe knowledge base, but what about Cultural Safety” (p. 1). With the student’s permission, cultural safety became the term that articulated for Ramsden the ideas that grew from that Hui. As a nursing educator and Māori, Ramsden had been funded to convene the Hui, which she did in her own traditional area to have the support of her own whānau and hapū. Her grandfather named Hui Waimanawa for the tears, literally streams that had flowed from the heart, the inner being, since the advent of colonisation. The name also captured the deep emotions felt that the gathering had been enabled to take place.

Cultural safety to Ramsden (2002) came to be about four objectives in nursing education. The first three deal primarily with educating student nurses and midwives about the category of difference between themselves and the receivers of their care, not “blame [ing] the victims of historical process for their current plights” (Ramsden, 2002, p. 94). The student nurses and midwives are “to examine their own realities and the attitudes they bring to each new person they encounter in their practice.... to be open minded and flexible [to difference]” (Ramsden, 2002, p. 94). The objectives in the category of difference prepare the nurse/midwife for the fourth objective, which specifically articulates the category of power and the subjective source

of its analysis. It is the receiver of the nursing/midwifery care who defines the experience of the power inherent in the caring process as culturally safe. This analysis by the subject sets cultural safety apart from both the cultural competence of other health professions, and transcultural nursing discourses (Ramsden, 2002)

The Nursing Council of New Zealand (2011) defines cultural safety as:

The effective nursing practice of a person or family from another culture, and is determined by that person or family. Culture includes, but is not restricted to, age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability. The nurse delivering the nursing service will have undertaken a process of reflection on his or her own cultural identity and will recognise the impact that his or her personal culture has on his or her professional practice. Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and well being of an individual. (p. 7)

Kawa is a formal Māori protocol and Whakaruruhau means ‘to protect, shield’ (Moorfield, n.d.-f). While cultural safety has come to cover any difference of a nurse from those who receive her or his care, Kawa Whakaruruhau relates to cultural safety for Māori and “protecting the unique issues of Maori through the Treaty of Waitangi relationship with the Crown” (Ramsden, 2002, p. 5). As this endeavour is grounded in Aotearoa New Zealand nursing praxis, and I am a Pākehā nurse researching Māori women in my place of employment, an urban marae-based Māori health provider, the categories of difference and power in the nursing theory of Kawa Whakaruruhau/cultural safety is relevant to researcher, researched and research site, and research as a critical theory. So, too, are the processes in Kawa Whakaruruhau/cultural safety of nurse/researcher self-reflection and subjective assessments by participants and research site. As nurse/researcher I reflect on my own historical roots in Aotearoa New Zealand and my values and beliefs as categories of difference in individual encounter and in ‘being’ in a marae community. The participants in, and the research site of this study, assess the Kawa Whakaruruhau over their wellbeing and mana in the encounter and beyond.

In contrast to cultural safety, cultural competence does not explicitly articulate the role of power within the health care context but focuses on health professional practice “by integrating culture into the clinical context” (Durie, 2001a), or similarly, the synthesis of culture and care in transcultural nursing (Leininger, 2002a). Durie (2001a) outlines “four domains of cultural

impacts [as]... health perspectives, values, symptom hierarchies, and community capacity” (p. 4). Gains for the health worker (medical profession) are seen as “conceptual understanding, professional practice, diagnosis, treatment and care” (Durie, 2001a, p. 4). It is arguable whether cultural competence addresses culturally safe health care systems, but attitudinal and service provision changes support health care engagement when Māori women experience cultural safety in safe practice and systems. There is a place for cultural competence as described by Western educated psychologist and acknowledged Indigenous healer Eduardo Duran (2006). Duran (2006) addresses particular therapies for Indigenous that are an amalgamation of Western and Indigenous therapies. Similarly, it could be argued that cultural competence is one of the intentions of Kaupapa Māori nursing programmes. But such cultural competence education and practice as valuable as it may be, is not the same as cultural safety. While cultural safety is a critical theory, cultural competence is not as it is not cognisant of power relations and context.

Durie (2011b) stresses that in health care cultural safety is a process and not the endpoint. The endpoint is the improvement of Māori health outcomes. “The practice of cultural safety in health services, for example, is not justified simply as a celebration of culture but as a means of achieving better health outcomes” (p. 52). However, Durie’s (2011) employment of ‘celebration of culture’ together with ‘cultural safety’ demonstrates his use here of cultural safety is not the critical power analysis envisaged in Ramsden (2002). Celebration of culture is here resonant of the teaching of student nurses prescribed waiata, and suggestive of Leininger (2002b) and transcultural nursing (Ramsden, 2002). In relation to that practice, Te Tiriti and constitutional lawyer, Moana Jackson, Ngāti Kahungunu, Ngāti Porou, as an interviewee in Ramsden (2002) succinctly commented, "I don't particularly want nurses to know how to sing waiata, I want them to treat my mother properly if she's unwell” (p. 88). Cultural safety could equally be described as a political theory to empower Māori and other recipients of care at all levels to wellbeing as Subject/s assessing at individual, system or structural levels, health care as safe (or not). Cultural safety at an institutional level includes all nurses being enabled to effectively practise their nursing skill set safely and with appropriate recognition, and in the context of this work, the cultural-clinical nursing skill set of Māori nurses (Huria, Cuddy, Lacey, & Pitama, 2014). Next, I will overview the structure of the following chapters.

Structure/overview of thesis

Literature Review

I review relevant literature in three sections: ‘Association of health care engagement with health outcomes’, ‘Health care engagement terms,’ and ‘Influences on health and health care engagement’. The first section reviews literature on the role of health services, structures and systems in health care engagement and health outcomes. The second section reviews a selection

of the vast literature on health care engagement terms, deconstructing an environment of blaming the recipient of health care. The third section reviews literature on factors influencing health and health care engagement, and specifically, ethnicity as experienced interpersonally, and through systems and structures.

Mapping the theoretical terrain

The theoretical terrain in a critical geography considers theories in which to make visible the relationship between knowledge and power. The first section on the geography of health considers the contribution to the terrain of the theories of whakapapa, marginality, geographies of women's health, and therapeutic landscapes. The locating and positioning of myself as nurse and researcher in the second section begins with an overview of representation, and the contribution of whiteness theory to the terrain. I reflect on the contribution of Kawa Whakaruruhau/cultural safety theory for nurses and representation of Pākehā (ness) in the eyes of Māori women to the processes of decolonisation. In the third section concerning the location and positioning of Māori women I review different colonialism theories, and the representations of Māori women as theorised by Māori scholars. Mapping the theoretical terrain makes knowledge and power relationships visible for the production of knowledge from the women's stories.

Methodology

The methodology chapter defends the choice of qualitative methodology and the method of unstructured interviews as appropriate to meet the aim of the study. As a nurse in a marae setting I had existing relationships that were all important to the study. Kawa Whakaruruhau as a critical theory informs the study and its processes from its inception as a practice issue, and in turn is informed by other critical theories. Recruitment processes, data collection and analytical processes are defended. The findings and discussion are presented as a critical geography of health. Reporting back, concluding the study and making recommendations are consistent with the theory of Kawa Whakaruruhau for participants and their whānau, and for KMHSS as the research site. I have reviewed the ethical requirements and rigor employed in the research.

Findings

The three findings chapters are presented as a geography of health where the term 'landscape' is employed as a metaphor and/or a physical reality to convey the complexities in the women's stories. Landscapes then may tell of the past (*Chapter Five*), of spaces and places and networks and connections (*Chapter Six*), and they are places where women remembered, and imagined with hope, a future for themselves and their whānau (*Chapter Seven*). In *Chapter Five: Generational influences and landscape: A whakapapa of health*, the interweaving of the whakapapa of land, language and health tells of the embodiment of historical trauma, intergenerational bodily remembering impacting health and health care engagement.

Disruptions to land and language and the passing down of knowledges through the processes of colonisation disrupted access to an economic base and for some to their sense of identity and wellbeing. There was place-making in the urban area and the ritualising of whakapapa connections, such as times of birth and tangihanga. The women sometimes presented generational influences as an enduring burden of risk of illness experienced in the whānau, and sometimes as embodiment of enduring illness and risk of complications.

In *Chapter Six: Contested landscapes: Space, place, networks and connections*, power relations and spatiality, and body as geography and body in geography comprise the main themes. Kawa Whakaruruhau as cultural safety in nursing relationships with Māori women and their whānau, foregrounds the impact of experiences of health care from positions of gender, ethnicity as Māori, poverty, age/generation, or life-stage. In *Chapter Seven: Therapeutic landscapes: Remembering and imagining an ideal*, the women remembered landscapes past and present, metaphorical and physical spaces and places, networks and connections and imagined for themselves and their children a landscape ideal. The women imagined going from marginal to centre of the service and offer practical ways for services to achieve Kawa Whakaruruhau, a safe mantle for Māori women.

Discussion, conclusions, and recommendations

The discussion chapter is framed by Hokowhitu's (2010b) question on Indigenous Peoples' interpretations of authenticity, and Indigenous (in)authentic identities since colonisation. The women's understandings of their whakapapa connections to traditional places, and to other whakapapa, their place-making in urban areas, are acknowledged inclusive and unique authentic identities contributing to wellbeing. (In)authentic identities associated with being Māori are the embodiment of the traumas of colonisation and experienced as risk of chronicity, inhabiting disease, and poverty disrupting health and health care engagement. Kawa Whakaruruhau at individual, whānau, health provider or programme, system and structural levels enable the women's inclusion in health care, and gives hope for the future. The limitations of the study are based on the heterogeneity of Māori women, and my positioning as a Pākehā woman, nurse and researcher. The study concludes acknowledging health care as a contested locale, yet in the women's visioning of therapeutic landscapes, there is hope. Landscapes past, present and future in a whakapapa of health inform difference and power in Kawa Whakaruruhau, cultural safety theory for nurses. Recommendations are for nursing, the research site, and research.

Summary

This chapter began with stories from my growing years, spots in time that with stories from my nursing practice became, with reflection, what has been termed a "burden of awareness" (Sheppard, Porter, Faust, & Nagar, 2009, p. 608). The awareness is of differences between

Māori and Tauīwi in the world in which I have grown and in my nursing practice affecting the health and health care engagement of Māori women. I have overviewed in this chapter Māori and European beginnings in Aotearoa New Zealand and the foundations of biculturalism. As a background to the women's stories I have briefly outlined the organisation of Māori social life, the unifying and foundational concept of whakapapa for whānau, hapū and iwi, and though a minority, the youthfulness and growth of the Māori population. Māori and Tauīwi health and socioeconomic disparities are set against health as a human right's issue.

I have described the research site, Kokiri Marae Health and Social Services and affiliates, including Mana Wahine Inc., within the historical and structural context of the development of 'by Māori for Māori' services. This led to the research aim. The qualitative methodology is informed by critical theory, including whiteness theory and Kawa Whakaruruhau/cultural safety theory and the findings presented as a geography of health.

To Sheppard et al. (2009) there are different ways for politicised members of society with a burden of awareness to act politically either individually, in communities, in society to make a difference in the world:

By direct action, voting, and creating discussions and dialogues that question common-sense views on controversial issues: issues of power and difference, us and them, development and backwardness, terror and patriotism ... Why don't you begin a new dialogue, embarking on your own journey to creatively embrace your own burden of awareness? (p. 608)"

Within the social justice agenda of nursing I answer, 'Here is my embrace'.

Chapter Two: Literature Review

To meet the aim of the study I have reviewed literature in three areas: the association of health care engagement with health outcomes, health care engagement terms, and influences on health care engagement. The association of health care engagement with health outcomes concentrates on the responsibility of health providers, systems and structures as seen in the disparities that exist between and within countries, with a particular emphasis on Aotearoa New Zealand. I have reviewed areas pertinent to the experiences of Māori women I encountered in my practice at KMHSS, including the women's concerned care of and for whānau. These are maternal health, and the non-communicable diseases (NCDs) of cancer and other long-term conditions, particularly when experienced as co/multi conditions, which are important health areas for all Māori women. Terms that are most used in literature on health care engagement are compliance, adherence, and concordance, the defining of which has ethical considerations. The third section begins with a broad overview of recipient of health care factors in the literature. I then consider the influence of ethnicity as a determinant of health. Forms of racism are recognised as being difficult to identify. Racism is implicated in literature presented in the first section, and in health and social disparities in *Chapter One: Introduction*.

Key words in the following areas were used to locate relevant literature:

- i. Māori, Indigenous;
- ii. adherence, compliance, concordance, attendance/non-attendance, delay in care, loss in care, loss to follow-up, treatment refusal;
- iii. cervical, breast, reproductive, maternal;
- iv. health, cancer, diabetes, metabolic syndrome, chronic;
- v. gender, women, race, ethnicity, class, socioeconomic.

Databases and tools used are Massey University's Discover search tool, which covers the Library Catalogue, Medical Literature Analysis and Retrieval System Online (MEDLINE), and Cumulative Index to Nursing and Allied Health Literature (CINAHL), Education Resources Information Centre (ERIC), and PsychINFO. Also used, including websites, were the Index New Zealand database (INNZ), Elsevier's bibliographic database, Scopus, Science Direct, and New Zealand Government websites such as Statistics New Zealand. Further articles have been sourced from article reference lists and informally.

The association of health care engagement with health outcomes

Health care engagement is associated with individual and population health risk (Munro et al., 2007), health care system finances (World Health Organisation, 2007), and the ethical imperative in the health systems and professions to prevent harm (Felzmann, 2012). Related to those concerns is an established literature associating health care engagement with health outcomes for women (R. B. Harris et al., 2012; Ministry of Health, 2014d; Peton, Gilham, Fletcher, & Matthews, 2004). In Aotearoa New Zealand, health care engagement is implicated in the disproportionate burden of illness and death of Māori women¹⁹ and has been associated with disparities due to socioeconomic status, ethnicity/racism, geography, age, gender and impairment (Poutasi, 2002; Robson & Harris, 2007; Robson, Purdie, & Cormack, 2010; Talamaivao et al., 2010). Against a global rise in diabetes and certain cancers, it has been established that a number of risk factors are shared, but risk factors are not shared equally within and between nations (Shi & Hu, 2014). The literature reviewed in this section mostly emphasises the contribution of structures and systems to health care engagement and health outcomes. A Te Tiriti and a human rights approach in reviewing selective literature on maternal health, cancer, predominantly cervical and breast, and other NCDs, is adopted to demonstrate health care engagement and health outcomes association.

Maternal health

Globally, there are an estimated 800 maternal deaths daily varying between and within countries (World Health Organisation, 2013b). Improving maternal health is a Millennium Development Goal, and maternal deaths have decreased as births assisted by trained health care personnel have increased (United Nations, 2014). The WHO promotes at least four antenatal visits each pregnancy, which in the period 1990-2012 increased from 37-52 per cent of pregnancies. International examples of identified Indigenous antenatal care issues are lack of quality data (Rumbold & Cunningham, 2008) and lack of cultural responsiveness (Reibel & Walker, 2010) for Aboriginal Australian women, and clinic culture clash with Indigenous beliefs in South Africa (Ngomane & Mulaudzi, 2012). At a site in Alberta, Canada, it was identified that over 40 per cent of Aboriginal women whose infants were HIV positive had not had any prenatal care (Bucharski, Brockman, & Lambert, 1999).

Antenatal care access, risk factor prevalence, prematurity incidence, and mortality profiles were identified disparities for Māori and similarly for other Indigenous and vulnerable groups, in a comparative study of maternity systems in Australia, Canada, Ireland, the Netherlands, the United Kingdom, the United States and Aotearoa New Zealand (Rowland, McLeod, & Froese-Burns, 2013). Independent risk factors were poverty, smoking during pregnancy, existing

¹⁹ *Chapter One: Introduction*

obesity, and ethnicity. In another Australian, Canadian, Aotearoa New Zealand, and United States comparative review health care engagement and other broad determinants of health were associated with Indigenous adverse birth outcomes (Smylie, Crengle, Freemantle, & Taualii, 2010). According to Smylie et al. (2010): “Generally, stillbirth is associated with maternal health and access to maternity care; neonatal death is associated with access to obstetric and neonatal care; and postneonatal death is more likely to reflect social and environmental factors” (pp. 8-9).

In Aotearoa New Zealand different monitoring systems exist. Maternal mortality is reported by the Perinatal and Maternal Mortality Review Committee (2014), while morbidity of serious and/or rare conditions in pregnancy, childbirth and postnatal through AMOSS²⁰(Australasian Maternity Outcomes Surveillance System, 2014). Both maternity service consumers with live births and whose babies had died between 20 weeks gestation and four weeks postnatal are surveyed for service satisfaction (Ministry of Health, 2012b). In 2006-2012 pre-existing medical illness and suicide were the most frequent, though indirect, causes of maternal mortality, half being identified as potentially avoidable and due to barriers to health care access and or engagement (Perinatal and Maternal Mortality Review Committee, 2014). Maternal mortality in 2012 was 16.0 per 100,000 maternities²¹, with Māori and Pacific women at three times greater risk of maternal mortality than women of other ethnicities. Women living in the 20 per cent most deprived geographical areas have a 2.5 greater risk of maternal mortality than women living in the 40 per cent least deprived areas, and more Māori live in deprived areas. Māori had the highest proportion of mothers less than 20 years of age, a group more likely to be economically disadvantaged and to have other risk factors, such as smoking and substance abuse. Māori had higher rates of stillbirth and neonatal death, than New Zealand European (Perinatal and Maternal Mortality Review Committee, 2014). In 2011, by maternal age,

²⁰ AMOSS *Australasian Maternity Outcomes Surveillance System*- a surveillance and research system combined with Australia.

²¹ ‘Maternal death’ is defined as “the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management. It does not include accidental death or incidental causes of death of a pregnant woman.... The maternal mortality ratio is calculated per 100,000 maternities.... [Maternities are] all live births and all fetal deaths [stillbirths and terminations] from 20 weeks or beyond or weighing at least 400g if gestation is unknown. Perinatal mortality is fetal and early neonatal deaths from 20 weeks gestation until less than 7 days of age or weighing 400g if gestation is unknown.... Neonatal mortality is all infant deaths from live birth to 27 days of age inclusive” (Perinatal and Maternal Mortality Review Committee, 2014, p. 4).

mothers under 20 years of age, and by ethnicity, Māori, had the highest infant death rates²² of all ethnic groups (Ministry of Health, 2014d).

Māori women's ratings of their own care in the *Maternity consumer survey 2011* showed they were relatively less satisfied with antenatal care, classified as a secondary area for improvement, and hospital stay had less satisfaction impact (Ministry of Health, 2012b). However, ways of care during birth and overall care provided by their Lead Maternity Carer (LMC)²³ had satisfaction impact. Information, before birth care, and after birth care were categories that only required maintenance. Māori had no priority areas for improvement. The survey method was a mailed letter and questionnaire with an online option sent to randomly selected women who had given birth between July and August 2010, followed by a postcard reminder for Māori and Pacific and follow up telephone interview for all selected women. The overall response rate was 40.9 per cent, the Māori response rate 23.2 per cent. Under-representation of Māori and Pacific, and women less than twenty-five years of age, were adjusted for by data weighting by age and ethnicity. However, Barnes et al., (2013) raise the question as to whether the *Maternal consumer survey* is appropriate for ascertaining cultural concerns with maternity services.

With Māori concepts of pregnancy and wellbeing as a base, Barnes et al. (2013) engage with the literature plus key stakeholders, and then review the epigenetic theory of environmental influences on gene expression, such as social determinants of health. In essence, from a life course approach, care for maternal health begins before the conception and birth of the mother. Inequalities in adverse birth outcomes, such as small for gestational age, may have life course effects on the infant. Levels of influence on that life course are the macro level of national and state systems including societal norms, values, and resource distribution; the mezzo level are community influences. Mothers and their babies inhabit the micro level, while health systems are exosystem influences.

Perspectives on maternal health care include its integration with general health care, providing accessible, culturally appropriate and responsive services, with screening for risk factors and monitoring of communication at entry to maternity care, acute referral, and exit (Rowland et al., 2013). Integrated health care to address existing and broader determinants of health are similarly aspects of the broad life course approach to maternal health (Barnes et al., 2013; Ratima & Crengle, 2012). Partnerships (Smylie et al., 2010), and leadership are required from

²² Infant death is death before one completed year of life.

²³ In Aotearoa New Zealand, the Ministry of Health contracts with the Lead Maternity Carer (LMC) chosen by the woman to oversee her total maternity care (New Zealand College of Midwives, 2015). The LMC may be a midwife, a medical doctor with a diploma in obstetrics, or an obstetrician.

both Indigenous and government in health policy, programme and service provision (Rowland et al., 2013; Smylie et al., 2010). Bucharski et al. (1999) describe an intensive community development process that led to the development of a culturally appropriate prenatal care model for Canadian Aboriginal women. The model included a life course approach that involved fathers and family members and was grounded in Aboriginal cultural beliefs, practices and community, including guidance by Aboriginal women leaders. Areas of research, monitoring and evaluating recommended by the literature are social and environmental conditions and support (Barnes et al., 2013; Smylie et al., 2010); best practice to address Māori maternal and infant disparities in health care engagement and outcomes (Barnes et al., 2013; Ratima & Crengle, 2012); later life mediators of adverse birth outcomes from a life course perspective (Ratima & Crengle, 2012); accurate Indigenous identification, and quality data systems (Rowland et al., 2013; Smylie et al., 2010).

Non-communicable disease: Cancers

Cancer is the most common cause of death for both men and women in Aotearoa New Zealand, Māori rates are inequitable (Ministry of Health, 2014b), and cancer control is recognised as a human rights issue (Seffrin, 2008). In 2011 the Māori female age-standardised cancer registration rate was 45.3 per cent higher, and the cancer mortality rate was 95.8 per cent higher than non-Māori females (Ministry of Health, 2014b). In a literature review on Indigenous Polynesians and cancer disparities it was unclear whether late stage of cancer diagnosis for Māori in comparison to non-Māori indicated, “delayed presentation, failure to detect early disease with screening programmes, or a more aggressive biology” (Dachs et al., 2008, p. 482). Nor was it clear if later diagnosis was the issue in poorer outcomes. An investigation of inequalities in cancer survival associated with ethnicity, social and geographical access to health care factors linked data from the New Zealand Cancer Registry (NZCR), NZDep²⁴01 and Census Area Units (Haynes, Pearce, & Barnett, 2008). The authors found extensive disease at diagnosis was more related to ethnicity than to deprivation. High levels of deprivation were adversely related to survival in most cancer types, mostly due to late presentation. Travel times to health care were mostly not statistically significant. Inequitable health care is one possible explanation posited.

Studies²⁵ on the worldwide prevention, incidence, prevalence, profile and mortality of cancer demonstrate disparities across and within countries (International Agency for Research on

²⁴ NZDep (plus year) refer to New Zealand indexes of socioeconomic deprivation (University of Otago, n.d.)

²⁵ Studies based on data from The *International Agency for Research on Cancer*, (IARC) a World Health Organisation cancer specialist centre based in France

Cancer, 2014; Soerjomataram et al., 2012; Stewart & Wild, 2014). Low resourced countries have limited access to the continuum of prevention, screening and early detection, effective treatment, and palliative care. Infection related cancers, such as cervical, liver and stomach cancers, are significant in low and middle resource countries, while cancers more related to industrialisation, for example, lung, breast and large bowel cancers are increasing. All cancer incidence and mortality is predicted to about double 2008-2030 (Bray, Jemal, Grey, Ferlay, & Forman, 2012; Chalkidou et al., 2014). Overall, health care engagement in cancer control on a population basis relies on political, structural and organisational factors outside the individual (Vineis & Wild, 2014).

There are a number of international studies that link women's health with the provision of, and women's access to, screening and treatment services for breast and cervical cancer (Anttila & Roncob, 2009; Arbyna, Raifua, Weiderpassb, Bray, & Anttila, 2009; Bos, Rebolj, Habbema, & van Ballegooijen, 2006; ElSaghir et al., 2011; ElSaghir et al., 2007; Howell, Gurusingheb, Tabnakc, & Sciortinob, 2009; Vaccarella, Lortet-Tieulent, Plummer, Franceschi, & Bray, 2013; Zucchettoa et al., 2010). Registers of all women, preventative call and recall screening services, clinical and laboratory services, and pathways to enable access to treatment are reported in a number of studies. The most risk of invasive cervical cancer and mortality was for those never screened or opportunistically screened. The UK national cervical screening programme was introduced in 1988 (Peton et al., 2004). A landmark study projected 1 in 65 UK women, then aged less than 50 years, would have eventually died from cervical cancer if they were never screened. Peton et al.'s (2004) modelling differed from previous studies that suggested that a national cervical screening programme was not cost effective in their estimation of lives saved (Raffle, Aiden, & Mackenzie, 1995; Raffle, Alden, Quinn, Babb, & Brett, 2003).

A substantial literature in women's health and cervical cancer in Aotearoa New Zealand exists concerning the so-called 'unfortunate experiment',²⁶ which led to the 1988 *Cartwright Report*²⁷ (Bryder, 2008; Bunkle, 2010; Chalmers, 2010; Frizelle, 2010; Jones & Fitzgerald, 2004; Paterson, 2010; Paul, 2004). Women were engaged in health care, but as Frizelle (2010) concludes, there was institutional failure where consent was inadequate and women harmed. As recommended, *The National Cervical Screening Programme* (NCSP) was established in 1990 to provide free screening for women 20-69 years and now claims to have reduced the incidence and mortality of cervical cancer since its inception by 60 per cent (National Screening Unit,

²⁶ The term 'unfortunate experiment' is attributed to Professor David Skegg and has been widely used in both academic and lay literature to refer to Dr Herbert Green's research 1966-1987 at National Women's Hospital, Auckland (Jones & Fitzgerald, 2004).

²⁷ *Chapter One: Introduction*

n.d.-a). Disparities in Māori women's health care engagement and health outcomes remain (Brewer et al., 2012; McFadden, Mc Connell, Salmond, Crampton, & Fraser, 2004; Priest et al., 2010; Robson et al., 2010). Cervical cancer accounted for 1.7 per cent of cancer registrations for women and 1.2 per cent of cancer deaths in 2011, with cervical cancer registration rates for Māori twice that of non-Māori, mortality rates 3.9 times higher than non-Māori (Ministry of Health, 2014b).

In a study based on the New Zealand Cancer Registry (NZCR) 1994-2005, delay in attending for a cervical smear, and for follow up treatment of an abnormal smear is associated with higher mortality rates from invasive cancer for Māori women compared to women of other ethnicities (Brewer, Pearce, Jeffreys, White, & Ellison-Loschmann, 2009). Further, over half of the registered cervical cancer cases had not been 'ever screened' before diagnosis, where 'ever screened' is defined as receiving at least one smear prior to six months before diagnosis (Brewer, Pearce, Jeffreys, Borman, & Ellison-Loschmann, 2010). The risk of being diagnosed at a late stage was considerably lessened with women who had been screened regularly, defined as "...no more than 36 months between any two smears in the period 6 - 114 months before diagnosis" (Brewer et al., 2010, p. 158). For Māori women the increased risk of a late stage diagnosis persisted even after adjustment for "screening history, SES (socio-economic status) and urban/rural residence" (Brewer et al., 2010, p. 163).

For women in Aotearoa New Zealand in 2011, breast cancer was the most commonly registered cancer (28.7 per cent), and the second most common cause of cancer deaths (15 per cent) (Ministry of Health, 2014b). For the period 2001-2011, the age-standardised breast cancer registration rate increased 18.6 per cent for Māori women and decreased 4.2 per cent for non-Māori women, a major disparity. In 2011 Māori women had a 1.4 per cent higher breast cancer registration rate and a 1.6 per cent higher breast cancer mortality rate than non-Māori women. Māori women experienced 25 per cent higher breast cancer mortality than non-Māori non-Pacific women for most of the 1980s/90s, based on the New Zealand Census-Mortality Study (Sarfati, Blakely, Shaw, Cormack, & Atkinson, 2006). The rate rose rapidly to a 68 per cent disparity 1996-1999. Free breast screening²⁸ introduced for women 50-65 years January 1999, extended to women 45-69 years June 2004 (National Screening Unit, n.d.-b; A. Richardson, Cox, Brown, & Smale, 2005).

Curtis, Wright and Wall (2005) found that while there are similar age-specific breast cancer incidence rates for Māori and non-Māori women under 50 years of age, 25-59 years total Māori

²⁸ BreastScreen Aotearoa (BSA)

women had age-specific higher mortality than non-Māori, and sole Māori women higher still. In a study on the ethnic and socioeconomic trends in breast cancer incidence between 1981 and 2004, the Māori age standardised rates were consistently higher than non-Māori, which with the difference in incidence between Māori and Europeans increasing from 7 per cent in 1981-6 to 24 per cent in 2001-4, was unable to be explained (R. Cunningham, Shaw, Blakely, Atkinson, & Sarfati, 2010). McKenzie, Ellison-Loschmann, and Jeffreys (2010) found that Māori women had lower breast cancer survival to four years than non-Māori women based on NZCR breast cancer registration data April 2005 to April 2007. Socioeconomic position was a strong predictor of lower survival in data linkage with NZDep, suggesting a relationship between poverty and breast cancer survival. A higher proportion of Māori (34 per cent) and the most deprived group had more missing data compared to the affluent group (7.5 per cent). More robust processes to ensure data completeness are critical. The studies support specific initiatives to enable Māori women's timely engagement with screening, diagnostic, and treatment services.

The disparity in Māori women's participation rate in breast screening has improved over time (Page, Morrell, & Taylor, 2014). The target biennial BSA participation rate for all women aged 50-69 years is 70 per cent and in the six-month period January 2012 to June 2012 it achieved 70.4 per cent, while for Māori women it achieved 63.5 per cent. In the period July 2010 to June 2012, the rates of invasive cancer were significantly higher for Māori than non-Māori women (Robson, Stanley, Ikeda, & Stairmand, 2014). The early detection of small tumours without nodal involvement was similar for Māori and non-Māori women, which the authors see as an encouraging sign of BSA's improving coverage and Māori women's participation over time. In the National NZ invasive breast cancer audit for 2008, 52 per cent of women were symptomatic referrals, 37 per cent screening referrals and women referred through screening had higher levels of conservation surgery (Ooi, Campbell, Kollias, & Silva, 2012). There was no ethnicity analysis reported for 2,371 women.

Cunningham, Shaw, Blakely, Atkinson, and Sarfati (2010) suggest that breast cancer mortality differences may be more amenable to intervention currently than possible incidence risk factors, supporting the association of health outcomes with health care engagement for Māori women with breast cancer. Chalkido et al. (2014) hold that inequities in cancer burden in high-resourced countries are maintained by commercial and political interests and are unsustainable. Racism as a factor is considered below.

Non-communicable disease: Co/multi conditions

The association of inequalities in health care engagement with health outcomes in prevention, early diagnosis, and treatment of non-communicable diseases (NCD) is demonstrated in a global and inter-country comparison of NCDs, including Aotearoa New Zealand (Cesare et al., 2013). Amenable mortality²⁹ has declined over 2000-2011 but Māori rates in 2011 were still 2.7 higher than non-Māori non-Pacific (Ministry of Health, 2014a). The leading causes of amenable mortality for adults 45-75 years were cardiovascular diseases and diabetes. In Aotearoa New Zealand one in three deaths are due to cardiovascular diseases. The age-adjusted disability rate in 2013 was 32 per cent for Māori, Pacific 26 per cent, European 24 per cent, and Asian 17 per cent (Statistics New Zealand, 2014). Over half of those with a disability had more than one disability and 41 per cent of disabilities were caused by an illness or disease. Māori women are about seven times more likely to have renal failure and about five times more likely to have a lower limb amputation concurrently with diabetes than non-Māori women (Talamaivao et al., 2010).

Through prevention and treatment, 80 per cent of cardiovascular illness (such as ischaemic heart disease and stroke) causing disability and premature mortality is potentially avoidable (Ministry of Health, 2014a). In 2011 35 per cent of all deaths were due to cardiovascular illnesses, and Māori women had 2.2 times higher age-standardised mortality rates from ischaemic heart disease than non-Māori women. Nearly 5 per cent of all illness, disability and premature deaths in 2006 were due to diabetes, with Type 2 the more common and largely preventable. After adjusting for age and sex, Māori were 1.8 times more likely to have been diagnosed with ischaemic heart disease, 1.6 times with asthma (1.7 for Māori women), 2.1 times with diabetes than non-Māori, and were 1.3 times more likely to suffer a stroke (Māori women 2.3 times) (Ministry of Health, 2012a). Thirteen per cent of Māori women were medicated for high blood pressure compared to 18 per cent of European women (non-Pacific, non-Asian). Risk factors such as smoking (41 per cent) and obesity (44 per cent), and higher unmet need for health care across all measures, such as access to health care or filling a prescription due to cost, are considered some possible explanations of Māori disparity in health status. There is literature that reviews the contribution of structures, systems and services to the documented disparities.

Aspin et al. (2010) fault the single system, professionally hierarchical nature of health institutions in Aotearoa New Zealand as acting against a co-ordinated equitable health care approach to people with co/multiple NCDs. The national policy framework and population health objectives address inequalities, but not the magnitude of the population with co/multiple

²⁹ Amenable mortality is deaths at ages 0-74 years that may have been prevented if primary or secondary health care access or effectiveness had been appropriate (Tobias & Yeh, 2007).

NCDs. Sheridan et al. (2011) studied district health boards (DHB) and their dependent primary health organisations (PHO) for equitable health care provision for people with NCDs on chronic care management. DHBs and PHOs are jointly structured in the health care system to be responsible for the health of the populations in their areas. Expert chronic care management informants from primary health were interviewed on Māori and Pacific cultural needs. In that period DHBs were found to have difficulty in planning and funding equitable services, including equity across geographical areas. Health equity for people with NCDs requires inter-professional teamwork and co-ordination mandated in policy and in health care provision (Aspin et al., 2010) and DHBs and PHOs need to address the culture and attitudes of their institutions (Sheridan et al., 2011). As reported by the local media, the Hutt Valley DHB four-year delay in appointing a Māori Partnership board at governance level, and Māori but not other community groups audit and contract threat, may be examples of DHB culture and attitudes to ethnicity for Hutt Valley DHB to address (Hutt News, 2014).

An Aotearoa New Zealand qualitative study explored core competencies for integrated teams working with people with long-term conditions with interdisciplinary health professional participants (Fouche, Kenealy, Mace, & Shaw, 2014). Themes garnered were: “teams and teamwork, professional roles and responsibilities, interprofessional communication, cultural competence, better engagement with patients, families, and carers, and common systems, information sharing and confidentiality” (Fouche et al., 2014, p. 534). Cultural competence and cultural safety were promoted interchangeably in Sheridan et al. (2011) and cultural competence was a theme in Fouche et al (2014). While both concepts may acknowledge the broadness of culture and patient or population differences from health care personnel, cultural safety but not cultural competence involves reflection on, and acknowledgement of, personal and provider power, including inter-disciplinary power, when working in teams to address inequity.

An evaluation of the implementation of Care Plus³⁰ in one PHO demonstrates an initiative where primary health care engagement improved health equity. The HbA1c³¹ disparity between Māori and non-Māori with diabetes reduced in two years, and systolic blood pressure and LDL³² cholesterol decreased for both groups (Kenealy, Eggleton, Robinson, & Sheridan, 2010).

³⁰ “Care Plus funding is provided to general practices to improve chronic care management, reduce inequalities, improve primary health care teamwork and reduce the cost of services for high-need patients” (Ministry of Health, 2014c)

³¹ HbA1c – glycosylated haemoglobin level – blood test to measure plasma glucose concentration over extended time periods.

³² LDL - low-density lipoprotein cholesterol

Health care engagement may have been supported by the dual Māori/non-Māori governance structure and the systematic and informed nature of Care Plus. Under Care Plus, the patient receives four publically funded, extended consultations involving a patient-centred self-management plan. Nurses in this PHO received training on Brief Interventions, Flinders self-management³³, diabetes, and a computer-based diabetes care template.

In a mixed method study to ascertain health professionals' views on Care Plus, characteristics of nurses, GPs, and practice organisations were identified that may improve clinical outcomes for patients with chronic and complex conditions (Eggleton & Kenealy, 2009). Nurse factors, according to Eggleton and Kenealy (2009), include “ patient-centredness, assertive follow-up, nursing knowledge and involvement of other health professionals. Practice organisation factors included dedicated appointment times, longer consultation time and low cost. GP factors included GP commitment and teamwork” (pp. 194-195). Primary health care nurses have a substantial role in long-term illness education and would appreciate further education and support, according to two Aotearoa New Zealand studies (Daly, Arroll, Sheridan, Kenealy, & Scragg, 2014; Gilmour, Strong, Chan, Hanna, & Huntington, 2014). Challenges with implementing practice interventions to improve equity for people with long term NCDs were identified in an Aotearoa New Zealand web-based survey of nurses who had received training for the Flinders Program (Horsburgh et al., 2010). Horsburgh et al. (2010) concluded: “Without addressing barriers such as infrastructure, adherence to funding streams, delivery systems and resistance from managers and some health professionals, the introduction of new and complex patient interventions in primary care remains difficult” (p. 293).

Internationally there are disparities between countries and within countries in maternal health, non-communicable diseases of cancer and other conditions, at times experienced as co and multi non-communicable diseases. The provision of equitable health care globally and locally supports access to health care engagement and improved health outcomes. Powerful hindrances remain.

Health care engagement terms

Internationally, a large literature across different health disciplines discusses recipient of health care engagement and outcomes, mostly using ‘compliance’, ‘adherence’ and ‘concordance’. Terms are often used in ways that position the recipient of health care as a problem, implying patient/consumer failure (Carpenter, 2005; DiMatteo, 2003; Eggleston, Coker, Prabhu Das, Cordray, & Luchok, 2007; Katapodi, Facione, Miaskowski, Dodd, & Waters, 2002; Yabroff,

³³ The Flinders Program was developed in Australia and promotes self-management of long-term conditions (Flinders University, 2014).

Kerner, & Mandelblatt, 2000). Given the individual, societal, and global implications of health care engagement, there are attempts to redefine the health provider/system approach to focus more on the recipients of health care (Marinker & Shaw, 2003). The World Health Organisation estimates medication adherence in long-term conditions to average 50 per cent in developed and less in undeveloped countries (Sabaté, 2003). Contemporary understandings of personal autonomy, at least in the Western world, and health self-management as a human right (World Health Organisation, 1986), stand against professional-centric approaches, for example, Vrijens et al. (2012) study reviewed below. Person or patient-centred care or shared decision-making; and expert patient or patient-provider partnerships variously acknowledge in clinical practice, research and policy the recipient of care's world, experiences of illness, health professional relationships and power dimensions (McKinnon, 2013; Snowden & Marland, 2012; Zill, Scholl, Härter, & Dirmaier, 2013). While there is an overriding concern with medication management, there is some literature, that to various degrees, references holistic care (Cohen, 2009; McKinnon, 2013; Sabaté, 2003; Snowden et al., 2014).

The terms compliance, adherence and concordance are often used interchangeably, with differences in conceptualisation across and within professions, resulting in meanings and application confusingly unclear (Bissonnette, 2008; Carpenter, 2005; Cohen, 2009). Other terms used less may include 'loss to follow up' (Lubega et al., 2013), 'non attendance' (Bos, Rebolj, Habbema, & van Ballegooijen, 2006), 'hard to reach' (Sykes, Sadler, & Priest, 2008), and 'delay' (Durie, 2001b; R. B. Harris et al., 2012; Pearce, Foliaki, Sporle, & Cunningham, 2004). Non-compliance and non-adherence may be described as intentional or non-intentional and have ethical implications (Bissonnette, 2008; Came, 2014; Segal, 2007; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Inappropriate prescribing and adverse drug reactions add to the complicated nature of medication adherence (Geurts et al., 2010; Horne, 2006; McGraw & Drennan, 2004; Munro et al., 2007). The lack of clarity in term definition has led to measurement challenges for clinicians, researchers and policy makers in standardising and clarifying practice and research. I will first review 'compliance', 'adherence', and 'concordance' definitions.

Compliance

According to an editorial by Fraser (2010), the concept of precise patient compliance to the doctor's orders began in the 1950's medical literature and is implicitly understood as good and rational (Vermeire et al., 2001) with the prescriber always right (Kaufman & Birks, 2011). In a 2001 review of three decades of compliance, adherence and concordance literature, Vermeire et al. (2001) found compliance to be the most commonly used term, the patient often absent in the compliance literature, and compliance to be differently defined across the disciplines, if it was

defined at all. Compliance is negatively associated with patient passivity and powerlessness in two nursing concept analyses of adherence (Carpenter, 2005; Cohen, 2009). However, Snowden and Marland (2012) define compliance as “the act of following an instruction” (p. 1355) and not necessarily negative if located within a concordant relationship, as further considered in *Ethical considerations* (pp. 37-38).

Adherence

In contrast to the passive patient, Carpenter (2005) suggests “adherence implies the active participation of the patient in the treatment regime” (p. 192). In 2003 the World Health Organisation, cognisant of the burden of long term illness individually, to families, populations, nations and globally, launched a report to influence adherence to long-term therapies, which was primarily focussed on health professions and systems (Sabaté, 2003). The report defines adherence as “ the extent to which a person’s behaviour–taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health provider” (Sabaté, 2003, p. 3). In a Canadian nurse’s study, Bissonnette (2008), critiques the report, that “... no association was made with a theoretical framework from which to operationalize adherence” (p. 637). In the concept analysis of adherence across nursing, medicine, psychology and pharmacy literatures, Bissonnette (2008) found there was no clear definition of adherence, no clear distinction between adherence and compliance, and no definition that was patient-centred and cognisant of behaviours and power dynamics inherent in adherence. The most common definition Bissonnette (2008) found was “the extent to which patients follow the instructions they are given for prescribed treatments” (p. 641).

Concordance

While compliance and adherence describe patient health behaviours, concordance suggests a recipient/provider of health care relationship involving “shared decision making and agreement...that respects the beliefs of the patient” (Carpenter, 2005, p. 192). McKinnon (2013) traces the “root principle” (p. 766) of concordance to the articulation at the 1986 World Health Organisation Ottawa Convention, of the basic human right for all people to participate in improving and having control over the determinants of their own health. The origin of concordance as a term in UK health care, McKinnon (2013) asserts, is the 1997 Royal Pharmaceutical Society of Great Britain’s [RPSGB] report, *From compliance to concordance: Shared goals in medicine taking*. An editorial following the publishing of the 1997 RPSGB report recognised the shift in power the change in terminology from compliance to concordance entailed in the recipient/provider of health care relationship (Mullen, 1997). According to Mullen (1997), “the concept of concordance suggests frank exchange of information, negotiation, and a spirit of

cooperation” (p. 692). While barriers to an “egalitarian” relationship are inevitable, “treating the patient as a decision maker is a fundamental step away from the compliance model” (Mullen, 1997, p. 692). The more equal relationship emphasises shared responsibility by “ setting out the goals of therapy and not arbitrarily enforcing a treatment regime” (Fraser, 2010, p. 95), with concordance better evaluated from the quality of health care relationships rather than health outcomes (Bissell, May, & Noyce, 2004). There remain differing views on concordance.

Concordance is argued as possible (Snowden & Marland, 2012) and rare, aspirational but not achievable (Kaufman & Birks, 2011), as covert for compliance (Armstrong, 2005; Segal, 2007), as different (Carpenter, 2005) or not different from compliance and adherence (Segal, 2007), and questionably, as possible in a physician-only 15 minute first consultation (Storm, Benfeldt, Andersen, & Serup, 2009). In a discussion document on medication and older people, McGraw and Drennan (2004), reject the negotiated and shared decision-making of concordance and the expert patient. The facticity of patient equality inherent in concordance is doubted (Cohen, 2009; Segal, 2007). The communication inherent in concordance is liable to distortion leading to “communication pathologies” (Stevenson & Scambler, 2005, p. 18), and is akin to the pharmaceutical industry rhetorically asking, “how are people persuaded to take more drugs?” (Segal, 2007, p. 83). With shared decision-making, concordance has been viewed as giving patients “consumer status in the doctor-patient relationship” (Armstrong, 2005, p. 26).

Health care teams with a mix of roles, skills and strategies (McGraw & Drennan, 2004) partnering in mutual respect with other professions and the patient in patient-centred endeavours support the culture of concordance (Horne, 2006; Krigsman, Fuchs, Nordström-Torpenberg, Pettersson, & Nilsson, 2007; Marinker & Shaw, 2003). Examples of team approaches are pharmacist consultations for new prescription education, to minimise side effects and individualise medication devices (Geurts et al., 2010; Horne, 2006; McGraw & Drennan, 2004) and specialist asthma nurses to whom patients may confide illness or treatment concerns (Horne, 2006). The health care team assessment and consultation process may involve motivational interviewing (M. Brown & Bennett, 2010), coaching (Barnett & Prashant, 2013), psychosocial profiling (Baines, Zawada Jr, & Jindal, 2005), or assessing and practically approaching health literacy (Bowskill & Garner, 2012). Social determinants of health and environmental contributions to illness, such as the association between healthy housing and respiratory health (Howden-Chapman & Bierre, 2008), don’t feature in health care engagement

literature although clearly a part of holism and a team approach in the patient-centred notion of concordant relationships.

Measurement

Measurement in the literature is both indirect and direct, and problematic (McGraw & Drennan, 2004; Vermeire et al., 2001), mostly concentrating on measuring patient medication compliance or adherence, rather than clinical outcomes from complying with, or adhering to, recommended lifestyle factors (Cohen, 2009). New technologies such as electronic prescriptions (e prescriptions) support medication measurement (Fischer et al., 2011), while measures of patient context are frequently ignored (Dunbar-Jacob, Sereika, Houze, Luyster, & Callan, 2012; Oberguggenberger et al., 2012; Vrijens et al., 2012). A German study presents a methodology, yet to be reported on, for the conceptualisation and measurement of patient-centredness for clinical practice and research (Zill et al., 2013). Some studies measure health professional/services 'concordance' with guidelines affecting women's health (Ess et al., 2011; van de Water et al., 2012).

Adherence measures mostly concern whether the prescribed medication was taken at all, or its effectiveness at prescribed dosages, times, and duration. Examples of adherence measures are self-report scale, physician-ratings, pill refill records and serum concentration to breast cancer endocrine therapy (anastrozole) (Oberguggenberger et al., 2012). Dunbar-Jacob, et al. (2012) used electronic prescriptions, pill count, self-report, and specific recall to measure adherence to a daily cholesterol-lowering regimen. Their finding of low correlation between the different measures demonstrates an issue across adherence research. Vrijens et al. (2012) proposed a universal taxonomy across different disciplines and Western countries: " 'adherence to medications,' ... 'management of adherence,' ... [and] 'adherence-related sciences'" (p. 696). While providing stages of adherence clarity, the taxonomy ignores recipient/provider of health care power differentials possibly as the authors view aspects of prescribing as "non-negotiable" (Vrijens et al., 2012, p. 694).

A medication self-management model developed by Bailey, Oramasion and Wolf (2013), is essentially a health professional six-step assessment tool to address non-intentional non-adherence, partially taking into account the patient's context: "fill, understand, organise, take, monitor, sustain" (Bailey, Oramasionwu, & Wolf, 2013, p. 27). Examples of assessment interventions are, financial support identified from the 'fill' or 'sustain' steps, or literacy assessment support needed to understand prescription instructions. The tool has the potential to identify barriers to medication self-management in the patient's context, and for the provider to identify gaps in their health care team support structure.

Snowden, et al. (2014) proposed a way to measure concordance in a concept analysis across health professions following Bissonnette's approach (2008). They submit that the lack of inter-professional agreement suggests the professional role determines understandings of concordant practice with implications for team approaches and measurement. The authors propose a research method that measures both the patient and professional view of a health encounter, correlates the two, then with an objective measure agreed upon by both parties determines the effectiveness or otherwise of concordance. The model may suggest that the power issues in the patient and professional relationship potentially could be addressed.

Ethical considerations

Bissonnette (2008) identifies a significant ethical dilemma for health professional judgement when patients have complete understanding of the consequences of their decisions and choose non-adherence to a prescribed treatment regime. Buetow's (2007) ideas on non-attendance as being both a rational and an irrational choice from different perspectives, challenges social norms that privilege attendance for healthcare and health. Based on rational choice theory and French sociologist Boudon's 'cognitive theory of action', Buetow (2007) questions the "ideological conception of attendance as a system of shared beliefs privileging professional expertise and values" (p. 598). The assumptions are firstly, a respect for the patient's personhood and moral agency, and secondly, persons tend to act rationally. A professional-centric view, according to Buetow, holds that non-attendance is irrational, denies the patient's personhood, and is marginalising and paternalistic. It maintains social power and control, tries to change rather than constructively respond to non-attendance, and damages the professional/patient relationship. In comparison, Buetow suggests a patient-centric view that holds non-attendance as subjectively rational. Subjective rationality could be either situational rationality, that is, due to circumstances, or procedural rationality due to psychological processes. Buetow's patient-centric view allows for women to choose a competing health value to appointment attendance and for future attending or attention to the defined health issue to be respectfully supported.

The ethical issues of "patient autonomy, paternalism and the public good" collide when the public good may be required to override the ethic of autonomy with paternalism, as in a public health emergency (Cribb & Barber, 2005). Felzmann's (2012) concise definition of paternalism is "neglecting, ignoring, or actively overriding a person's preferences in order to prevent harm or achieve a benefit for them" (p. 407). In an Irish case study, Felzmann (2012) discusses the various elements and stages of informed consent, which is generally held to counter paternalism, but the potential power imbalance within the process may itself be ethically problematic.

Compliance could be ethically justified, Felzmann believed, if an assessment determines the patient is incapable of giving informed consent and the health professional acts under the ethic of preventing harm. Horne (2005) identifies two different agendas: the “scientific/clinical agenda” and the “normative agenda”(p. 34). The scientific/clinical agenda is a measurement agenda, while the good and right of the normative agenda sets it in a moral framework. “Informed choice” and “supported adherence” become “informed adherence” to satisfy both agendas (Horne, 2005, p. 39). Informed choice characterises intentional adherence and is absent from non-intentional non-adherence (McGraw & Drennan, 2004).

Snowden and Marland (2012) and Felzmann (2012) identify concordance as an ethical and relational, patient-centred concept of choice. To Felzmann (2012) concordance is a therapeutic relationship based on relational and care ethics and with “a certain degree of emotional responsiveness” (p. 411). Health professional goals are not imposed but rather are cognisant of the perspective of the patient and each relationship is understood as contextual and valued for itself, not merely to effect medication adherence (Felzmann, 2012). To Snowden and Marland (2012) concordance is “a way of working together with people” (p. 1354). Compliance and adherence are “simply distinct concepts” (p. 1354) that may be a result of the shared care of concordance, but concordance is “an end in itself” (p. 1358). They conclude, “when concordance is achieved, adherence naturally follows where appropriate, as the mutual agreement, and not the outcome of this agreement, has been prioritised.” (p. 1359).

To McKinnon (2013) power sharing, as in Mullen’s (1997) egalitarian relationship, occurs when there is “true shared decision making” (McKinnon, 2013, p. 767), which aligns with the ethical concept of patient autonomy in psychology. With a human rights understanding, McKinnon (2013) applies concordance to the broad spectrum of nursing practice. He recognises the power in the nurse-patient relationship as foundational to concordance; for example, enabling the patient to shape the service they feel they need to receive for their wellbeing. Concordant power sharing in a nurse-patient relationship allows for meaningful, patient assessment and a feedback pathway to effect change. Referring to student nurse education, concordance to McKinnon is more than an ethic; it is a “fundamental principle underpinning the care process” (p. 770).

I have reviewed the health care engagement terms, compliance, adherence and concordance, and noted the confusing lack of clarity in use and definition, with implications for measurement and inter-professional teamwork within the health care system. Ethical considerations inform health care engagement theory and concordant relationships could be argued as dependent on cultural

safety. The third section refers to literature on various potential influences, then more specifically the influence of ethnicity on health and health care engagement.

Influences on health and health care engagement

Māori women's disparate socioeconomic determinants of health and health status have been included in literature above and outlined in *Chapter One: Introduction*, and are influences on health and health care engagement often experienced with ethnicity. In this section international literature is introduced that recognises multiple factors broadly and briefly that may influence health care engagement, before reviewing literature on influences based on ethnicity on health and health care engagement.

Factors affecting health care engagement

A UK report identified potential inequalities for the health provider to address that could affect shared patient-provider decision-making (Department of Health, 2012). Without equitable information, communication and support, factors such as gender, sexual orientation, ethnicity, culture, (dis)ability including learning (dis)abilities, age, religion or belief, and/or social economic positioning could impact shared decision-making. Braille resources were an example of communication support. In the context of cardiovascular risk reduction, Cohen (2009) adds environmental influences to support a healthy life style, modelling and interactive support by family and peers, and broader societal factors such as access to parks, healthy food, and support structures. Recommendations to support patient decision-making are health providers knowing more about health economics models (Elliott, Shinogle, Peele, Bhosle, & Hughes, 2008), social contexts (Vermeire et al., 2001), and the patient's preferences, including communication preferences (Farin, Gramm, & Schmidt, 2013). Health provider communication across the continuum of cancer care (prevention, screening, diagnosis, treatment, survivorship) influences health care engagement (DiMatteo, 2003).

Health, illness and treatment beliefs are associated with recipient of health care decision-making (DiMatteo, 2003; Horne, 2006; Hugtenburg, Timmers, Elders, Vervloet, & vanDijk, 2013; Segal, 2007; Waller, McCaffery, & Wardle, 2004), which is sometimes aligned with patient motivation (Cohen, 2009; Vermeire et al., 2001), anxiety (Brunton, Jordan, & Campbell, 2005; Neilson & Jones, 1998; Nelson, Geiger, & Mangione, 2002) and knowledge (Snowden & Marland, 2012). Snowden and Marland (2012) see health beliefs as a form of risk-benefit analysis that may be elicited by simply asking a question. An example of a health belief may be a perceived threat (Carpenter, 2005). Literature on influences on health and health care of Indigenous and minority populations begins with health care team relationships.

Foundational to health care for minority and Indigenous populations in the international literature are patient/population-centred relationships with their health care team based on mutual ‘understanding’, ‘respect’, and ‘collaboration’ (Bissell et al., 2004; Lie, Carter-Pokrasb, Braunc, & Colemand, 2012; Schoenthaler, Allegrante, Chaplin, & Ogedegbe, 2012). The health care team’s understanding of power is a sub-theme in cross-cultural minority/Indigenous health care relationships. An Australian discussion paper suggests Western scientism is a structural barrier for Indigenous Peoples where compliance to treatment is compliance to Western medicine (McConnel, 2003). To improve the measure of Indigenous compliance, McConnel calls for Western medicine to recognise and acknowledge its own hegemonic culture, then to fuse with Indigenous cultural beliefs to create shared knowledge.

An US Indigenous insider’s qualitative study on linguistics and health praxis advises a power shift from Western medicine to create a “dialogic space” for Indigenous process and relational ideologies of health (Dana-Sacco, 2012, p. 7). Health literacy and cultural differences in health values and beliefs between recipient and providers of health care create misunderstandings (Lie et al., 2012). It is the health care teams responsibility to address the gap. Lie et al. (2012) propose a collaborative health care team pedagogy that combines health literacy and cultural competence. Lie et al. (2012) stop short of promoting critical analyses of recipient and provider power differentials or inter-professional health care team dynamics. The English speaking participants of Pakistani origin with type two diabetes in a UK study revealed doctors not understanding their material and structural contexts, rather than health beliefs, were barriers to their self-management (Bissell et al., 2004). The influences of ethnicity on health and health care engagement are more closely reviewed.

Ethnicity

Disadvantages experienced due to ethnicity in health status, life expectancy, and in social determinants of health (as overviewed previously), are recognised by the international community as a violation of human rights to equality, freedom and dignity (United Nations, 1965, 2012). Such disparity is named “racism, racial discrimination, xenophobia and related intolerance” (United Nations, 2012, p. 14). In the literature, racism may be experienced as intended or not intended, and at the individual and/or population levels (Shavers et al., 2012). The influences of racism on health and health care engagement may be through health professional attitudes and behaviours (such as stereotyping or racial profiling, discrimination, prejudice or bias), the nature of health and other systems and structures of society (institutional racism), or the effects on individuals of experiencing racism in society (perceived

discrimination, prejudice or bias). Internalised racism is an effect of personally perceived discrimination, prejudice or bias on the basis of ethnicity (hooks, 1995³⁴; Huria et al., 2014).

Institutional racism occurs where even “seemingly benign policies, practices, structures, and regulations... have the potential to be discriminatory” (Shavers et al., 2012, p. 953). Health care systems themselves are seen as a determinant of health and therefore subject to enacting discrimination (World Health Organisation Commission on Social Determinants of Health, 2008). The United Nations (2012) urges states on the basis of statistical information of ethnicity-based health disparities to establish programmes that enable non-discriminatory access to health care and other social determinants of health. Ethnicity influences in the International and Aotearoa New Zealand literature is now reviewed noting the problematic of identifying and tracking ethnicity-based discrimination in health care settings.

Health care system

In Aotearoa New Zealand equity in health care for those who experience avoidable differences in health is articulated at a national level (A. King, 2000; McCreanor & Nairn, 2002; Sheridan et al., 2011). But there is literature that suggests health care is racist and contributes to health inequalities for Māori violating human and Indigenous rights (Curtis et al., 2010; Ellison-Loschmann & Pearce, 2006; Riddell, Jackson, Wells, Broad, & Bannink, 2007; Tobias & Yeh, 2007). Racism as inequity in health care alongside a higher proportion of Māori in deprived areas is not consistent with the principles of Te Tiriti o Waitangi (Baker et al., 2013; Ellison-Loschmann & Pearce, 2006; The Royal Commission on Social Policy, 1988). In general, genetic explanations for ethnic disparities in health status do not play a major role in population and public health terms (Ellison-Loschmann & Pearce, 2006; McDermott, 1998; Paradies, Montoya, & Fullerton, 2007). Systemic contributions to disparities include the complexity of the health care system, health provider attitudes (Wilson, 2004), and professional-centric services (Buetow, 2007). The Aotearoa New Zealand health system is said to demonstrate “...the (under)valuing of Māori lives and health within this country” (Robson & Harris, 2007). Literature examples follow.

Māori as directors or employees in the public health system have simultaneous dual roles and dual and different accountability models to Tauīwi directors and employees, they encounter racism, and their roles and accountabilities to Māori are generally not recognised (Panoho, 2012). Panoho (2012) studied the experiences of Māori directors on DHBs following the legislating of Māori representation in regional health governance. Māori directors experienced

³⁴ *bell hooks* (lower case first letters) is the non de plume of author Gloria Jean Watkins <http://www.egs.edu/library/bell-hooks/biography/>

board silence when engaging with Māori health issues, paternalism when advocating for Māori health resource, and they faced marginalisation, isolation, and racist stereotypical roles and competency expectations. Māori directors often had to address the knowledge deficit of their fellow board members on the links between colonisation and health, while they fulfilled their DHB director role simultaneously with their Māori governance role.

Similarly, a qualitative study found Māori registered nurses were recognised for their clinical skills but not for the Hauora Māori skills they brought to their practice, potentially leading to Māori nurses feeling overworked and undervalued (Huria et al., 2014). Māori registered nurses reported experiencing racism at personalised, institutionalised, and internalised levels and similar to the Māori directors in Panoho's (2012) study above were unrecognised information resources for non-Māori peers (Huria et al., 2014). In Kenny (2011), a qualitative study on miscarriage with Māori midwives and other Māori women, some midwives or their clients reported experiencing "marginalized care as a result of care providers' views and/or judgments regarding ethno-cultural difference" (p. 281). Huria et al. (2014) suggested strategies to address the racism and support retention of Māori registered nurses such as a dual cultural clinical skills recognition system as promoted by Ratima et al. (2007). Culturally safe learning environments for non-Māori nursing students and registered nurses in engaging with Te Tiriti and cultural safety could be through Hauora Māori and non-Māori institutional nursing education partnerships, and through non-Māori supporting other non-Māori with on-going knowledge development (Huria et al., 2014).

There is a discourse that blames Māori for the disparities they experience (McCreanor & Nairn, 2002). In a discourse analysis with 25 Tauīwi general practitioners in Aotearoa New Zealand's largest city, Auckland, Māori disadvantage in health care was seen "as a function of being Maori" (McCreanor & Nairn, 2002, p. 5). The general practitioner participants associated non-compliance with individual responsibility and defended prevailing policies and health care provision. Genetic and Māori socioeconomic and cultural interplay explanations underrated the effects on Māori health of Aotearoa New Zealand's historical and political colonial legacy. While some participants enunciated what worked in their health care provision with Māori, there was an egalitarian discourse in service provision. The study authors called for a "consideration of the paradigms within which doctors operate, and analyses of the power relations that underpin everyday interactions of general practice" (McCreanor & Nairn, 2002, p. 7). Amenable deaths are a measure of the significant disadvantage for Māori women and women in deprived areas in Aotearoa New Zealand's health care system (Tobias & Yeh, 2007).

Tobias and Yeh (2007) found that approximately one third to one quarter or more of group disparity could be explained by amenable causes in health care, as when Māori receive different treatments to Tauwiwi. Metcalfe, Laking and Arnold (2013) found that Māori with high health needs, “heart disease, infections, diabetes, mental health and respiratory disease” (p. 14) had less medicines dispensed than Tauwiwi populations, were less likely to collect their dispensed prescriptions and after the initial dispensed medicines, had less subsequent scripts. The research compared burden of disease categories with medicines on the New Zealand Pharmaceutical Schedule for the year 30 June 2006-1 July 2007 and found Māori with high needs had nearly one million (19%-37%) less scripts than non-Māori. Non-subsidised medicines were not collected in the data and the authors suggest it is possible medicines were prescribed but not presented for dispensing. Pacific data was included in the non-Māori data so that the true rate of disparity for Māori in comparison to non-Māori non-Pacific was not determined (Metcalfe et al., 2013).

The study by Riddell et al. (2007) on a primary health organisation’s ongoing dataset on cardiovascular disease (CVD) supports the Sheridan et al. (2011) study on DHBs and PHOs difficulty in planning and funding equitable services for people living with chronic conditions, implicating behaviours and attitudes at all levels. Riddell et al. (2007) found CVD risk assessments did not meet current age-specific guidelines for Māori yet Māori had higher CVD risk factors such as family history, tobacco consumption, body mass index, cholesterol and blood pressure levels. There was CVD management data for only 58 per cent of the cohort with known CVD risk factors and more Māori (66 per cent) than non-Māori (57 per cent) had completed risk assessment and management data. Less than half of those (Māori 48 per cent, non-Māori 44 per cent) were receiving recommended evidence-based triple pharmacotherapies for the secondary prevention of coronary heart disease. Riddell et al. (2007) also found that Māori with ischaemic heart disease were about half as likely as non-Māori (18 per cent to 30 per cent) to receive revascularisation treatments. Wang et al. (2013) in a hospital coronary artery bypass graft cohort found Māori European disparities in CVD risk factors, procedure baseline characteristics, 30-day mortality rates, and related morbidity.

International literature shows influences of amenable causes on ethnicity-based differences in health outcome. Health professional communication involving recommendation of health screening has been shown to be effective (Lee-Lin & Menon, 2005) and in a US self-report study (telephone survey) on colorectal screening physician recommendation was effectively associated with attendance for screening for both African Americans and Whites (Wilkins et al., 2012). However, interpersonal and institutional racism is implicated. In a rural area with high colorectal cancer, African Americans had lower screening rates, 20 per cent higher incidence

and 45 per cent higher mortality compared to Whites. African Americans were less likely to have had a physician recommend colorectal cancer screening, their screening status was less likely to be current, and if screened, the mode was more likely to be a faecal occult blood test. Whites were more likely to have had colonoscopy or flexible sigmoidoscopy. It may be African Americans attended their physician less than Whites and that recommendation and screening test differences were for real or physician-presumed financial reasons. Perceived behavioural attitudes and treatment as different may be experienced as discrimination affecting health and health care engagement.

Perceived racial discrimination is associated with poorer health and inequalities, in studies of respondents to the 2002/2003 and 2006/7 New Zealand Health Surveys who self-identified ethnicity, and Māori reported most racial discrimination (R. B. Harris et al., 2012; R. B. Harris, Cormack, & Stanley, 2013; R. B. Harris et al., 2006). Racial discrimination measures were verbal or physical attacks, or unfair treatment by health professionals, at work or buying or renting a house, and NZDep 2001 and NZDep2006 were linked for area socioeconomic deprivation respectively. Racial discrimination was usually associated with socioeconomic deprivation, which in itself demonstrates institutionalised racism, as defined above (p. 39). Māori who were assigned as European by others reported advantage and better health than Māori who were assigned by others as non-European, suggesting racism as a determinant of health (R. B. Harris et al., 2013). The experience of racial discrimination from a health professional may affect Māori women's utilisation of breast and cervical screening services, and experiencing racism generally affects health care use contributing to poorer health outcomes (R. B. Harris et al., 2012). Māori respondents reported as racially discriminatory behaviours from health professionals: not being listened to carefully, not having a full discussion of the information, or not being respectfully treated with dignity.

In a case study of 'Māori hospitalisation experience' Māori were found to have shorter stays in hospital than Tauwiwi and to have received sub-standard care (Wilson & Barton, 2012). Using 'average length of stay data', semi-structured interviews, and a literature review, the authors found that Māori did not experience the hospital as a healing place but rather as a personally and culturally isolating space where beliefs and customs were not accommodated. Doctors and nurses communication around their condition, procedures and treatment was felt discriminatory despite nursing's cultural safety mandate. Knowing the extent of disparities for Māori is dependent on accurate ethnicity counting.

Ethnicity counting

Measuring and monitoring disparities between Māori and Tauīwi has a complex, political, and contested history initially based on a biological ‘race’ approach to counting people (Cormack, 2010). Until recently ethnicity data was often the service provider’s assessment from the appearance of the health care consumer, based on blood quantum, or ‘not stated’ (Curtis et al., 2005, p. 2). Self identification, identifying with more than one ethnic group (Statistics New Zealand, 2005) prioritising Māori in data sets where there is more than one identity (Māori then Pacific, then European and Other), then became established in Aotearoa New Zealand (Curtis et al., 2005). Placing Māori at the centre of the enquiry rather than a subset and gathering quality data with statistical power enabled “the principle of ‘equal explanatory power’” (Curtis et al., 2005, p. 2). Recognition of multiple ethnicities allows for comparisons to be made within the Māori category, between those who identify solely as Māori and Māori with multiple ethnicities (Didham & Callister, 2012).

However, for Māori the extent of the inequalities may at best be an estimate as Māori data are known to be significantly undercounted (Bécares, Cormack, & Harris, 2013). Poor quality ethnicity data is itself an inequality. Lack of robust data hinders identification, assessment, and monitoring of health inequalities (Blakely, Robson, & Woodward, 2002; McFadden et al., 2004). An example is in a 2014 report of the national breast screening programme, BreastScreen Aotearoa, where the accuracy of the ethnicity data was not known making it difficult to monitor breast screening outcomes for Māori women (Robson et al.). Ensuring data accuracy of incidence, prevalence and impact of different diseases for Māori potentially addresses an aspect of racism.

Summary

I have reviewed selected literature to provide a framework to meet the aim of the study. Beginning in *Chapter One: Introduction* relevant disparities between Māori and Tauīwi in health and the social determinants of health are presented to highlight Te Tiriti breaches contributing to the health status of Māori women. In *The association of health care engagement with health outcomes* section of this chapter I reviewed the areas of maternal health and NCDs of cancer and co/multi long-term conditions, cognisant of health as a basic human right. Cultural responsiveness, quality data, and given the risk profile of Māori maternity, integrated general and maternity services and services with a life course focus, are identified for service and system development. In international cancer control, individual woman’s health is affected by political, structural and organisational factors outside her control. Internationally and in Aotearoa New Zealand there is evidence in the literature that links the provision of breast and cervical screening services and women’s timely access to screening and treatment to women’s health. While Māori women’s access to screening and treatment has improved, disparities

remain. Co/multi conditions are significant areas of health care for Māori, and there are new models of primary health care. Powerful interests potentially impact delivery.

There is an extensive literature on the health care engagement terms compliance, adherence, and concordance, which I argue potentially indicates how the client or patient is powerfully viewed by health professionals. The terms are variously defined, often according to health professional interests and role, which has the potential to influence inter-professional team work in clinical practice and research. Frequently, the recipient of health care is viewed negatively.

Compliance and adherence may be viewed as behaviours, and concordance as an aspirational descriptor of the relationship between health provider and recipient of care. An analysis of concordance and cultural safety could add to nurses understanding of therapeutic relationships with individuals or groups.

Recognised influences on health and health care engagement are wide ranging in the literature requiring proactive health provider responses. The influence of ethnicity on health and health care engagement may be hard to detect and may be intended or not intended. Ethnicity-based disparities between Māori and Tauīwi in health and in the determinants of health are viewed as the result of the influences of ethnicity in society. Māori recipients of care and Māori employees at all levels experience disparities at individual, system and structural levels in the health care system. In the next chapter I will map the theoretical terrain.

Chapter Three: Mapping the Theoretical Terrain

To map the theoretical terrain of Māori women's health and health care engagement in Aotearoa New Zealand is to engage with its social, historical and intellectual context characterised by "complexities and deep divisions" (Schostak, 2006, p. 6). Geographies in the social sciences are concerned with the relationships between a population and their physical and social environments, and the association of those relationships with the health and wellbeing experienced by that population (Gesler, 1992; House, Robbins, & Metzner, 1982). The physical and metaphorical mapping of relationships and associations in this geography begin with a childhood location that has geography of place for me, providing metaphor for considerations of a critical geography of health. It was where in critical reflection, Kawa Whakaruru hau reflection, the concepts of whakapapa, bodily remembering and cultural memories, marginality and therapeutic landscape, as related in particular to the geographies of women's health, first took shape.

My ethical and political intention is for the research to be an emancipatory project within the social justice mandate of nursing (J. Harris & White, 2013). The challenge in a critical geography is to locate and position myself as both nurse and researcher within the research, the participants who are urban Māori women, the topic and research site. Positioning enables power relations to be examined that may contribute to inequities experienced by Māori women at individual, health care provision, and population levels and in this research. Researcher representation involves discourses on whiteness and power and privilege. The views of Māori scholars are considered in the re-presentation of Māori women, as are discourses on the social and historical context and imperialism and colonialisms. The location and position of both the marae-based Māori health provider that is the research site and the topic have been considered in *Chapter One: Introduction*. I begin the mapping.

Geography of health

While geographies may engage both qualitative and quantitative approaches (Dyck, Lewis, & McLafferty, 2001), the conceptualisation of the health of Māori women as geographies is based on social constructionism. Social constructionism broadly holds that "... the world we experience and the people we find ourselves to be are first and foremost the product of social processes" (Cromby & Nightingale, 1999, p. 4). The social and discursive processes of our experienced world relate both to the medium of language (Cromby & Nightingale, 1999) and to the construction rather than description of the world (Burr, 1999). The material world is the entire physical world, its nature and form, ecosystems, social structures such as poverty, and the bodies in which we live our lives. Both the discursive and material worlds are embraced in this

geography of health contributing to a critical theory of research based on nursing praxis with possibilities of radical transformative practice. For example, in the words of herising³⁵ (2005):

In deploying the term "research." I insert a critical position where historical conditions and relations are centralized within the need and desire to change contemporary social and political conditions.... I understand research to mean re/search/in-g: that is, the ongoing social, historical, and political dialectical processes whereby students, disciplines, and practices are engaged in renewal, critical interruptions, and critical praxis. (pp. 129-130)

I recognise that 'mapping' is a Western construct, however, the imbued meanings of place and space are significant in traditional Māori cultural memories across time as noted in *Chapter One: Introduction*. Place and space vary as concepts by discipline (Leung & Takeuchi, 2011). In public health, space as location gives an exact location for disease exposure or spread within the population. In sociocultural geography coordinates of spatiality and external dimensions of time are seen to connect interdependently across physical, social, cultural and political realms affecting health (Anthamatten & Hazen, 2011; P. Jackson, 1989; Najafi & Shariff, 2011). The phrase, 'sense of place', demonstrates the social and cultural relationship between place and environment fundamentally comprising "rootedness, belonging, place identity, meaningfulness, place satisfaction and emotional attachment.... physical environment...." (Eyles & Williams, 2008, p. 5). Places and spaces are not neutral, rather they connect with the complex power relationships that are inherent in the location of various identities of ethnicity, gender, sexuality, socioeconomic, cultural, urban/rural (Fredericks, 2009). Private and public spaces and places connect (Meleis, 2011) with "... multiple, interlocking dimensions from the structural to the personal" (Kemp, 2011, p. 6) and as such are argued as appropriate for mapping health and health care engagement.

The study is positioned away from the biomedical paradigm of health to seek an understanding of the interconnections in the lived experiences of Māori women, which contrasts with comparative studies (Dyck et al., 2001; Keenan, 2009). Gesler and Kearns (2002) contend that: "Biomedical ideologies stress the biological as opposed to the social, cultural, political and economic causes of disease; reinforce the hegemony of the medical 'expert'; and create widespread acceptance of disease classifications that may not have local cultural relevance" (p. 53). Comparative studies may compare Māori with Pākehā where the privileged norm of which feminists have long argued is white, middle class and male (Dyck et al., 2001). Moana Jackson (2009) contends that in the Māori intellectual tradition the comparison of people is to their own cultural and historical context. While I do not (could not!) position this work from the Māori

³⁵ Lower case first letter as in text, *herising* (2005)

intellectual tradition, mapping landscapes from Māori women's stories of places and spaces and their interconnections physically and metaphorically may be seen as compatible with Māori intellectual tradition. As such it comprises a critical geography and I begin with the concept of whakapapa.

Whakapapa and metaphor

Space, place, connections and networks past, present and future, which contribute to intergenerational wellbeing (or not) are contained within the concept of whakapapa. As such whakapapa as metaphor contributes to an understanding of Kawa Whakaruruhau, cultural safety in the whakapapa of land, language and health for Māori (Mikaere, 2011). It is to my own geography of place, and to metaphor, that I first turn.

Ko Ruapehu te maunga

Ko Whakapapa te awa

Ko Ōwhango te kāinga

Ruapehu is the mountain, Whakapapa the river, Ōwhango the village

From Mount Ruapehu's source, the sky, melting ice, snow, and connecting tributaries, strengthen the Whakapapa River from thin stream down steep ravine to large channel through rapids, pools, dam, gorge, and changing current to its mouth on the Whanganui River, the depths of the Tasman sea, and skywards precipitation. Whakapapa is a metaphor of connections, and in this geography of health tells of resistances, marginalisations, losses, ebbs and powerful flow, of cycles of life. The cultural lens through which Māori make sense of their world is embodied in the conceptual framework of whakapapa (Mikaere, 2011). The Māori conceptualisation of whakapapa is as "a basis for the organization of knowledge in respect of the creation and development of all things" (Barlow, 1991, p. 173). Atua, all creation, and all people have whakapapa. To know one's whakapapa is to have a foundation, sense of place, of belonging, of relationship to one another past and present. (Cody, 2004; Mikaere, 2011; Ministry of Justice, 2001; Waitangi Tribunal, 1997). Whakapapa informs identity and may be experienced as unity, connectedness and interdependence.

It allows us to explain where we have come from and to envisage where we are going. It provides us with guidance on how we should behave towards one another and it helps us to understand how we fit into the world around us. It shapes the way we think about ourselves and about the issues that confront us from one day to the next. (Mikaere, 2011, pp. 285-286)

As a geography of health, the framework of whakapapa embodies one's sense of place in the

world and of experiences that contribute, or not, to wellbeing. For Māori disruption in knowledge of connections to land, language, and tikanga may potentially diminish wellbeing. The association of place with health is demonstrated in the embodiment of historical and intergenerational trauma, between the colonial losses by elimination and displacement of Indigenous Peoples and their languages and intergenerational health outcomes (Leung & Takeuchi, 2011; Walters, Beltran, Huh, & Evans-Campbell, 2011). Mikaere (2011) speaks of an interconnected whakapapa of “language struggle.... landlessness state of health” (p. 295). Intergenerational and historical trauma is argued in this thesis as an embodiment of the loss of whakapapa of land, language and health. Understandings of this embodiment are possible in the theories of bodily remembering and cultural memory.

Whakapapa as bodily remembering and cultural memory

Whakapapa links back to the beginning and provides guidance for the future (Mikaere, 2011). Linking back, *remembering*, and to the future, *imagining*, connect to seminal philosophical works on memory by literary scholar, Casey (2000), who argues for the centrality of the body in any assessment of remembering. To understand the process of bodily remembering is to elaborate on “physical location, bodily sensations, and the iterative effects of a lifetime of living through episodes of pain and suffering in the creation of memories” (E. Cartwright, 2007, p. 259). Casey (2000) contends there are two activities of bodily remembering: body memory, and memory of the body. Bodily remembering involves past actions and present re-enactments with certain characteristics (Casey, 2000). The habitual nature of body memory to Casey (2000) suggests, “The past is *embodied* in actions. Rather than being contained separately somewhere in the mind or brain.... [It implies] prior enactment and experience” (pp. 149-150, author’s emphasis). Casey looks to the active Latin root: “ ‘Habit’: *habēre*, to have, to hold. To be habitual is to have or hold one's being-in-the-world in certain ways” (p. 150). Habitual re-enactments in the present have their own history.

A "habitude" (as we may call any habitual tendency toward re-enactment) becomes an active ingredient in what we are doing in the present.... a subtle structuring of behaviour along the lines of a personnel or collective tradition that becomes readily reinstated in certain circumstances. (Casey, 2000, p. 150)

The characteristics of habitual body memory are “Efficacious, orientating, and regular” (Casey, 2000, p. 151). Efficacious habitual body memory creates outward difference and inward sameness. It may be movement of some kind as opposed to inertia, as in this study, acting for survival in a circumscribed way to effect survival in the face of change, overwhelming loss of land and language, place and memory. The way we settle into any new situation is to establish

orientating habits to provide a base for other more complex activities. The new habits help us to both become, and to stay familiar, with the new surrounds, as constant and on-going disorientation would be incalculably difficult. Habitual body memory operates simultaneously at a "deeply prereflective level " (p. 152) and is regular. This alliance of prereflection and regularity allows for spontaneity within a framework previously laid down. To focus on the rules and form of the action would be to hinder spontaneity and deny regularity.

In bodily remembering memories are both individual and collective, and are embodied by being held in the body rather than in the mind, and may be activated by place (Casey, 2000).

Rodríguez and Fortier (2007) theorise that present ideas about illnesses are remembered in the body from one generation to the next, not in a biological essentialism, but as cultural memory. "Since culture is learned behavior, and is intended to lead to an ongoing adaptation to the social and environmental contexts, it necessarily falls or rises on the strength of its enculturation process" (Rodríguez & Fortier, 2007, p. 108). The enculturation process involves the remembering of past events by groups of individuals and in the work of Rodríguez and Fortier (2007), it was seen to be shaped by religious, political, class, and family social forces. Cultural memory is passed down the generations and impacts the choices a People group will make as to how they live and what they do. The passing down, or not, is at both conscious levels and unconscious levels. Casey's (2000) 'commemoration' is similar; "body and place memory conspire with co-participating others in ritualised scenes of co-remembering" (p. xi).

It is possible that 'bodily remembering' is portrayed in Grace's (1998) novel *Baby No-Eyes*, by her character, Te Paania, speaking about the old people living the traumas of colonisation:

Sometimes there is a story that has no words at all, a story that has been lived by a whole generation but has never been worded. You see it in the old ones, you see it in how they walk and move and breathe, you see it chiseled into their faces, you see it in their eyes. You see it gathering in them sometimes, see the beginning of it on their lips, then you see it swallowed and it's gone. (p. 18)

Bodily remembering and cultural memories may be argued as a whakapapa enacted both consciously and unconsciously in a geography of health, both to enhance wellbeing and as ongoing internalised oppression. There are stories that are told and there are stories without words that are unconsciously lived daily; historical trauma embodied. Marginalisations, resistances, interconnections and intergenerational cycles affecting wellbeing are next mapped beginning with the second metaphor of place from my childhood.

Marginality

The current of the river, the place of most power in the moving of its water, is most often in the middle. But like the Whakapapa River, the awa near the edge of the bush by the mill town of Ōwhango where I grew as a child, differing rock formations produce resistance and the water is forced around the resistance and over changing gradients altering the position of power. The current comes to have strong energy on the far margin of the river against a rock edge producing a long stretch for fun swimming to those who know to find it. Meanwhile, those disempowered and lacking access to health and its social determinants may well live life on the margins differently through the intersections of gender, sexuality, ethnicity, colonisation, and often socioeconomic status (Erai, 2007; McManus, Abel, McCreanor, & Tipene-Leach, 2010; Pihama, 2001; Stewart-Harawira, 2007).

Hurley (2007) defines marginality as: “Sets of relations that are indicative of structures of social, political and/or economic inequality and/or disadvantage; and, the cultures of the people who are affected by these structures” (p. 172). The disparities in health and its social determinants may be a factor of poor access to what Hurley (2007) sees as social goods: “health, education, income, security, social respect and social participation” (p. 162). Consumer and social citizenship for Māori women may be seen as predicated by a history of negative legal citizenship such as human rights abuses, the outcomes of the intersections. Marginality to A. Smith and Pitts (2007) “depends not so much on an objective reality but on the power of the people or institutions framing the concern to position specific populations or groups in specific ways” (p. 6).

The locating of Indigenous peoples on the margins, as other and lesser, has been a global phenomenon through the powerful processes of imperialism and colonialism (L. T. Smith, 2012; Wilson & Barton, 2012). Linda Tuhiwai Smith (2012) draws our attention to the development of modernity, the Western scientific method, and the production of knowledge in the marginalising of Indigenous Peoples by imperial and colonising forces. From the perspective of knowledge creation, what comprises “truth” in research has marginalised other ways of knowing (L. Brown & Strega, 2005). The emergence of alternative ways of assessing power relations, such as critical analyses of the intersections above, have shown the diverse ways Indigenous women are marginalised, “centring subjugated knowledge(s)” (L. Brown & Strega, 2005, p. 8). The margins in physical and metaphorical geography are not static places (Hurley, 2007). As with the Whakapapa River, the margins may counter with resistance to force the flow and change the place of most power to the strong current against the margin of the opposite bank. Those marginalised through societal structures may resist a disempowered status and force powerful changes. Research changes from objectivising the margins to

“research by, for, and with them/us” (L. Brown & Strega, 2005, p. 7). Resistances have transformative possibilities.

The geographies of women’s health

In addition to the intersections above, geographies map the ways women’s health is defined and responded to, the ways women carry the burden of care for themselves, their family, environment and economy, and the ways women access resources as consumers or providers (Dyck et al., 2001). In a further geographical conceptualisation, the body as geography is experienced whether well or ill in everyday spaces illustrating the social construction of the body (August, 2005), and health and illness, for example, cervical screening (Lovell, Kearns, & Friesen, 2007). Through geographies of women’s health linkages are made between the ‘personal’, and local and global processes.

While it is recognised that geographical place has significance for Indigenous peoples, concepts of place and space are also significant for Indigenous women in their relationship with health services (Dyck et al., 2001). The significance of place for Māori is seen in the concepts around whenua, used for “ground, country, afterbirth, placenta” (Ryan, 1995, p. 319). Ūkaipō may refer both to being nurtured and suckled as a baby and to the place where one grew up in childhood (Barlow, 1991, p. 143). It is the place to return to after death for burial in the whenua with the iwi (bone or nation, see *Glossary*), bones of one’s tīpuna/tūpuna (forebears). “Place and space” may be where women are “culturally safe” (or not) to seek health care and notions of distance may relate to the “social and functional” nature of service provision (Manderson, Kirk, & Hoban, 2001, p. 178). Physical distance to health services may be an issue even in an urban area. Landscape influences therapeutic possibilities.

Therapeutic landscapes

The concept of therapeutic landscape initially evolved from cultural and medical geographies by scholars of Western traditional healing places (Gesler, 1992; Gesler & Kearns, 2002; Williams, 2007). Therapeutic landscapes are “associated with treatment and healing” (Gesler, 1992, p. 736) and may be seen as an “ideal”, or a goal for which to strive (Gesler & Kearns, 2002, p. 137). Traditional Western healing places Gesler (1992) suggests have various “physical, individual and social factors” (p. 743) interacting and layering into therapeutic landscapes. A comprehension of their attributed healing processes could aid hospitals, clinics, and other treatment, and less Western-focused places of healing. The consideration of health implications of social interaction with place has included the healing potential of wilderness experiences in physical landscapes or in everyday spaces such as home and work environments (Pranikoff & Low, 2007). No particular landscape can be assumed to be innately therapeutic; rather it is how

an individual or group interacts with the landscape that engenders it as therapeutic (Anthamatten & Hazen, 2011).

Silences and exclusions affect landscapes, and landscape "involves as much what is *excluded* as what is *included* in view or perception" (Kearns & Gesler, 1998, p. 7, authors' emphases).

While powerful interactions within place and space have their own importance, where and how places are planned and designed within and without, and with whom, impacts the health status of intended users (Kearns & Gesler, 1998). Fredericks (2009) describes health environments established by government and dominant group women for Aboriginal women that demonstrated "colonial representation, power, and social and political meanings" (p. 49). As outsiders to the target population, dominant group health care providers may assess a health service as adequate, which an Indigenous insider may find culturally inaccessible, and experience it as exclusion.

In a study of hospital waiting rooms, Crooks and Evans (2007) found that beyond the architecture are health promotion and regulatory notices that act as boundaries and regulate the way patients and visitors should behave in specific areas, affecting emotions and healing. When service users are not part of the design process, they are reflected within the social, political and economic values by their absence, which for Fredericks (2009), and for this study, is Indigenous women. To an Indigenous insider, an Indigenous health care setting with Indigenous inclusion in planning and design, that facilitated cultural exchange, such as family visitors and the bringing of meals, may be experienced as a therapeutic landscape. From mapping various material and discursive strands of geographies of health as an interconnected whakapapa of place and space and health, I turn to the location and positioning of researcher and representation.

Location and positioning of myself as Pākehā, nurse/researcher

Said (1978/2005) argues that no knowledge in the human sciences can ever be produced without the author acknowledging the powerful influences of their own circumstances. So I examine representation generally, then whiteness and privilege, imperialism and colonialism, white guilt, oneness and the question of 'when does a settler become a native'? (Ahluwalia, 2001/2005). My understanding of the outcome of Tauwiwi/Pākehā privilege is Māori disadvantage. Ways forward are seen in the decolonising method of as white seeing oneself (myself) through the eyes of those who see Tauwiwi/Pākehā and see coloniser, oppressor.

Representation

One critique when researching cross-culturally is that what is written says more about the writer than it does about the subject (Said 1978/2005). Said (1978), a Palestinian Arab, studied 19th

century English literature on the Orient, not to increase his knowledge of the Orient but to analyse the variety of ways domination was played out and distinction between Orient and Occident created. Said (1978) recognised his debt to Foucault who was interested in the relationship of knowledge and power inside changing societal discourses (Foucault, 1976/1978). However, as a Frenchman, Foucault's experience of power relationships contrasted considerably with Said's. To Said (1978), Foucault differed in not acknowledging the importance of the print of the individual author on their text, whereas Said was interested in each writer's contribution to the collective field. Foucault's influence showed Said how knowledge and power were connected in the inclusions and exclusions, both overt and covert, of what was considered legitimate knowledge in different disciplines. In turn, a feminist critique of Said's work, *Orientalism* (1978), noted Said's own lack of acknowledgement by exclusions of both the contribution of female writers and of women's "agency" (Lewis & Mills, 2003, p. 2).

Researcher's representations of their social positioning may be unknowingly incomplete as Harding (2007) wonders whether as individuals, researchers "are capable of voluntarily identifying all the relevant cultural assumptions that shape their research practice" (p. 54). Further, social statements used to locate the researcher and to serve as a researcher disempowerment strategy, leave it to the reader to determine how that location has shaped the project. To overcome this Roulston (2010) believes in researcher positioning broadly within social theory and in making explicit the theories that inform the research.

To Foucault (1994) knowledge and power in themselves are both neutral and hazardous: "Power is neither good nor bad in itself. It is something perilous" (p. 400). The relationship of knowledge and power is implicated in a Pākehā nurse and researcher choosing to research the topic of Māori women, health and health care engagement. While rooted in nursing praxis, highlighting the topic for research and as a nursing practice issue can locate the problem as being a 'Māori' problem (A. Smith & Pitts, 2007). Naming Māori women as the group of focus may draw attention to the characterisations of the group being the characterisation of all who may identify as Māori. The women's stories risk tokenism, "by being made 'representative' of the whole, in order to take the opportunity to speak the issues of the many" (A. Smith & Pitts, 2007, p. 164), disallowing the diversity of experience and location of others in the social group.

The emancipatory ideal of the project may also be of interest to other external organisations to manage other health and social service care obligations. Participants who are disempowered by virtue of their health and health care context may be further disempowered if the interpretation of the topic reflects the researcher so that a warped version of the participant's values, beliefs

and behaviours are promoted to powerful interests. Harding (2007) cautions, "...that even the most well-intentioned researchers lack some of the resources that the researched possess- resources that can be used critically to evaluate researchers' own taken-for-granted conceptual frameworks" (p. 53). Representation of health and health care engagement may be viewed an oppressive discourse of the dominant and powerful about the oppressed. To engage with a topic concerning health and disparities is "...to engage the many layers of oppressive discourses and practices that maintain and perpetuate injustice" (Pihama, 2001, p. 25). Naming a population as marginal may be more subjective than objective reflecting the welding of power in defined situations (A. Smith & Pitts, 2007). Re-presenting disparities and health, and health care and urban Māori women, is to acknowledge power relations inherent in the naming. Harding (2007) cautions those power relations are virtually permanent. Unrecognised knowledge and power in researcher representation may be dangerous as the consequences are not seen (hooks, 1995). So I acknowledge different discourses concerning being Pākehā beginning with whiteness and privilege.

Whiteness and privilege

The study of whiteness and its associated privilege is relatively recent (Fine, Weis, Powell Pruit, & Burns, 2004). Fine et.al (2004) write, "White standpoints, privileged standpoints, were generally taken as a "benign norm" or, in some cases, the oppressive standard- either way escaping serious scrutiny" (p. vii). The invention of white privilege and power is ascribed to European colonists as a means of asserting control over Indigenous other through processes of exclusion and difference based on colour (Martinot, 2010). Whiteness produced solidarity in the new colonies, and sociopolitical systems of administration based on race developed. Rather than babies being born equal in their humanness, a racial category was bestowed at birth with the idea of constructing a class hierarchy with white as privilege, as norm. As a social category race is institutionalised throughout the European and colonist structures of society thus affecting every level.

The colour-ranked relationship between whites and others has been described as "dependency" (Martinot, 2010, p. 23) and as "symbiotic" (Fine, 2004, p. 246). Both terms describe the need for whites to racialise others to produce and maintain privilege and power. The rankings of social determinants of health and in access to health services (Talamaivao et al., 2010) may be viewed as the ranking of the symbiosis of Tauīwi/Pākehā and Māori founded on the global phenomena of imperialism and colonialism.

Imperialism and colonialism

Marxist scholars date the beginning of modern imperialism as the pre-capitalist fifteenth century when Christopher Columbus voyaged to the Americas while endeavouring to sail to India

(Desai & Nair, 2005; Loomba, 2005). In the sixteenth century colonies were established to provide for the growing capitalist societies. The modern era of colonialism proper is described as the time when a few European states gained control over most of the rest of the world in the nineteenth century so that by 1930 84.6 per cent of land worldwide was colonised (Loomba, 2005, p. 19). Imperialism is connected with the acquisition of land and the dispossession of Indigenous People on that land who were thought to “*require* and beseech domination” (Said, 1993, p. 8, author's emphasis). Said (1993) uses the term “imperialism” to mean “the practice, the theory, and the attitudes of a dominating metropolitan centre ruling a distant territory” and colonialism “almost always a consequence of imperialism, is the implanting of settlements on distant territory” (p. 8). Loomba (2005) defined colonialism simply as the “...conquest and control of other people’s lands and goods” (p. 8). The attitudes of imperialism to the experiencing of the culture of ‘other’ across different imperial countries has been reflected in the language, art and culture that treated colonised peoples as inferiors in all relationships, and deserving of brutal punishment for any dissent or misbehavior (Said, 1993). Identity of ‘other’ is a cultural construction for the purposes of domination.

Sovereigns in imperial systems have subjects who both agree to be ruled and agree to provide the resources needed for the sovereign to reign (L.T. Smith, 1999/2005). Linda Tuhiwai Smith (1999/2005) argues for four aspects of imperialism: i) Imperialism was a structure for economic development for the imperial country. ii) With conquest, displacement and subjugation of the inhabitants of ‘new’ lands, the Indigenous population’s demise was expected (Ahluwalia, 2001/2005; L.T. Smith, 1999/2005). iii) Imperialism from the fifteenth century and the Enlightenment period produced an ideology associated with “the development of the modern state, of science, of ideas and of the ‘modern’ human person” (L.T. Smith, 1999/2005, p. 97). iv) Linda Tuhiwai Smith (1999/2005) names ‘colonisation’ as a fourth aspect of imperialism as an analysis of colonisation shows the complexities of imperialism in both Indigenous and heterogeneous Settler populations. While Indigenous populations were subjugated, the white Settler population was subject to contests for power and wealth from within itself.

Colonialism is often either viewed, firstly, as a historical past, or secondly, as a present specific geographical location under colonial rule (Mutua & Blue Swadener, 2004). Modern European colonialism initiated a complex economic system whereupon the colonised nation became inextricably tied to the coloniser in the exchange of human, natural and manufactured resources. For example, the loss of knowledge or access to traditional food resources, and dependency on European goods, to which some European denied Māori access, contributed to Māori devastation in Aotearoa New Zealand during the 1918 influenza pandemic (Rice, 2005). A third aspect of colonisation is when people are deprived of “their power for self-definition and

self-expression by being cast in the role of marginalized Other” (Mutua & Blue Swadener, 2004, p. 12). Other colonial discourses are the ‘one sovereign nation’, and settlers and identity and belonging.

One nation and becoming a native

In speaking of identity and national character in Australia, Pal Ahluwalia (2001/2005) uses the question posed by Mahmood Mamdani of Africa, “When does a settler become a native?” (p. 500). It is a question connected with coloniser and colonised, with the origins of the initial white settlers and the origins of subsequent white and non-white settlers, with the birth in the colonised country of whites and their ensuing relationship to the imperial country, and to the people their forbears came to displace. The question is connected to being a ‘subject’, to being a ‘citizen’ and to exclusion. It is connected to gaining and maintaining power, the hegemony of the white Anglo-settler population and the representation of ‘other’.

McDermott Hughes (2010) in his analysis of whites in Zimbabwe and their relationship to the nation, found whites focused on belonging to the land and environmentalism in a way that rendered other, the existing inhabitants, invisible except for serf-like use. A conditional form of belonging proposed by McDermott Hughes (2010) is to recognise the superficiality of white history and limitations of knowledge, and "...to stop ignoring social problems by romancing the land" (p. xix). Sibley (1995) and Tyler (2012) make similar connections between the English landscape in the presence of affluence, and white national identity and belonging. Exclusions include People of colour associated with empire on whom English capitalists depended for cheap labour.

The discourse on belonging to the land is connected to the oneness discourse powerfully and divisibly articulated in Aotearoa New Zealand in 2004 by the then leader of the opposition, Dr. Don Brash. Brash (2004) claimed Settler status as equal to Indigenous status, a white privileged interpretation of Te Tiriti o Waitangi downplaying Settler breaches that have disadvantaged Māori. Māori as other to white privilege are cast as deficient and largely responsible for their plight and remedy. The hegemonic articulation of whiteness seeking to belong to the colonised land, subjugates the Indigenous other’s identity, values, beliefs and understandings through the promotion of assimilation into the dominant white-privilege framework (hooks, 1995). Rather than oneness of racial harmony, it is divisive and blind to its ideological and material advantage.

Through intersections of gender, class, culture, geography, and ability, whiteness is not necessarily experienced as privilege and power. Common US vernacular of ‘white trash’ and ‘hillbilly’ are connected particularly to the identity of Appalachian whites (Henderson &

Tickamyer, 2009). Henderson and Tickamyer (2009), name the intersections “duality of Whiteness” (p. 60), and Garner (2007) concerned to centre race in the analyses of complex social issues, “the whiteness problematic” (p. 174). Also considered inferior in the racial hierarchy at different periods are the not-so-whites, for example, Irish, Jewish, and Asian Peoples, in an intersect of racism and classism (Brodkin, 2004). Politicisation of race has led to other understandings and whiteness theory terms.

White racial dualism and white guilt

Indigenous renaissance in Aotearoa New Zealand, Australia and Canada occurred concurrently, and was influenced by various protest movements including the civil rights and Black liberation movements in USA in the 60s and 70s³⁶(L.T. Smith, 2012; Taonui, 2013; Walker, 1990). Often urbanised into substandard communities, Māori were radicalised by their conditions and the assimilationist political environment³⁷. Other protest movements are seen as having been instructive for (often) young Māori radicals, such as the anti-Vietnam war, feminist, and anti-apartheid movements including protests excluding Māori and South African Black People in rugby tours with South Africa. Taonui (2013) suggests that this politicisation led to the “Māori land march (1975) and the occupations of Raglan golf course (1977) and Bastion Point (1978)” (p. 3) and to calls to honour Te Tiriti o Waitangi, for example, with the revitalisation of the Māori language and culture, such as the establishment of Te Kōhanga Reo. However, Webster concludes (1998) that the Māori renaissance may have benefited some Māori and some Pākehā, but not the majority of Māori society.

Winant (2004) argues the abolition of segregation laws in the US led to the problematising of race. The new order left fractured identities and an unknown hierarchy termed by Winant (2004) “white racial dualism” (p. 4). The new politicisation and egalitarianism has been seen as rendering whites colour blind to their own whiteness and associated power and privilege. The reaction to affirmative action programmes for African Americans has been for whites to feel disadvantaged similar to the discourse on choice rather than rights, and the one sovereign state in the Brash (2004) speech above. The establishment of Māori health care providers is based on Māori rights to health and health care in a space and place that is Māori rather than on Māori privilege in having a choice of provider as Brash (2004) argues. Following the reporting of Brash’s speech, McCreanor (2005) undertook a discourse analysis of a newspaper article with

³⁶In 1952 Auckland University instituted academic studies on the Māori language in the Anthropology Department with the title “Māori Studies”, which was long before “Black Studies” were introduced into American Universities (Hokowhitu, 2010b, p. 13). According to Webster (1998), ‘Māori Studies’ had been called for since 1908 but there had been resistance, and even in 1952, study of what is essentially an oral language was not thought to have been academic.

³⁷ Māori saw the Māori Affairs Act 1953 and the Māori Affairs Amendment Act 1967 as discriminatory against their traditional land interests (Webster, 1998, pp. 157-158).

interviews from the general Pākehā public. Perceptions of Māori privilege, as in health equity programmes, and a general agreement on being one people were themes of white racial dualism. White racial dualism may also be seen, for example, in the claiming by King (1999) of Indigenous status in Aotearoa New Zealand by descendants of European settlers, with which McCreanor (2005) disagrees. In King's (1999) Indigenous claim he ignores the power and privilege in white supremacy, and in the self-focus of King's claim, he could even be displaying white guilt.

'White guilt' is a term to describe uncomfortable feelings whites can have when focused on their inaction to the problems of racial discrimination and inequality (Lewis & Mills, 2003; Lorde, 1983/2003). White guilt is self-focused and can be both personalised and group-based (Iyer, Leach, & Crosby, 2003). In an European American study, white guilt was a predictor of support for compensation based on restitution but not of increased opportunity programs to promote equality (Iyer, Leach, & Crosby, 2003). Similarly, in a Netherlands study with an advantaged group, the appeal to moral ideals rather than to obligations produced more favourable attitudes towards social inequality and affirmative action (Does, Derksa, & Ellemersa, 2011). Both studies demonstrate the political imperative to understand white guilt and how to frame policy, and indeed this research, using white guilt appropriately for the purposes of addressing social inequality. Moral ideals of health as a human right may produce more favourable white attitudes in addressing social determinants of health for Māori than McCreanor (2005) found.

Much of the education of whites on white privilege and the effect on other has been by women of colour. Audre Lorde (1983/2003) as a black lesbian feminist called on white women to see that differences in women through race, sexuality, class and age needs to be recognised as a "crucial strength...defined and empowered" (p. 27) to move past patriarchy and white men's racism. The efforts of black and third world women to educate white women about their conditions was wasted energies that should be going to women moving forward together. Speaking at New York University Institute for the Humanities Conference Lorde (1983/2003) challenged, "I urge each one of us here to reach down into that deep place of knowledge inside herself and touch that terror and loathing of any difference that lives there. See whose face it wears" (p. 28). That call is represented in divesting of white privilege processes.

Divesting white privilege

How one acts as white determines one's whiteness (Martinot, 2010). Whiteness as with other racial characteristics, is a social construct based on ideas of purity with boundaries that act to exclude, and to maintain privilege. Martinot (2010) argues that whiteness with its ideas of

purity is anti-democratic, and whether one believes in white supremacy or not, that by identifying with a white tradition, one is identifying with racialisation processes. Concepts of oneness as democracy (Brash, 2004) and colour blindness as national ideal (Brash, 2011) are social constructs, 'everyone being like me (white) or you are deficient' and thereby on Martinot's (2010) argument, anti-democratic. Divesting of white privilege begins with the individual level but I will appropriate Martinot's argument on anti-racism and anti-colonality to show it cannot stay there. First, a definition of decolonisation as could be applied to nursing practice at the individual level, for example, as in my clinical or research practice with a Māori woman, her whānau, or the marae community.

bell hooks' (1995) definition of decolonisation is the process of, "unlearning white supremacy by divesting of white privilege if we were white or vestiges of internalized racism if we were black..." (p. 264). While hook's task for Black Peoples (or for Māori or other Indigenous Peoples) is not for me to work on, I can refer to Lorde's (1983/2003) call above and to Martinot's (2010) suggestion for divesting of white privilege. By seeing ourselves through the eyes of those as a social group we oppress, three things would happen, and I write as a Pākehā, as being seen as white (Lorde, 1983/2003; Martinot, 2010). Firstly, the oppressed person would be granted a subjectivity and we would see ourselves judged, not as an individual but as a member of a social group of privilege. Secondly, we would lose the ability to see the oppressed person as a racialised object, which would impact on our own identity making as people of white privilege. Thirdly, we would see how we had de-humanised those whom we had formally oppressed, both individually and as a social group because that's how it is seen in the eyes of those we had racialised.

Decolonisation as divesting of white privilege is at the heart of the requirements for Kawa Whakaruruhau/cultural safety in nursing practice, education and research in Aotearoa New Zealand.

In the neo-colonial environment this requires a profound understanding of the history and social function of racism and the colonial process. It also requires a critical analysis of existing social, political, and cultural structures and the physical, mental, spiritual and social outcomes for people who are different. (Ramsden, 2002, p. 180)

Decolonisation requires both a private decision for action by those individuals and services in the social category of whiteness, and an immense public social movement to abandon racialisation structures and processes (Martinot, 2010). Meanwhile, Kawa Whakaruruhau/cultural safety for the study participants is determined by them, and a mechanism for no harm is my awareness as researcher of the privilege and hegemony I hold

inherent from being white, from my Pākehā(ness) in Aotearoa New Zealand. The corresponding location and positioning is that of the women who participated in this research.

Location and positioning of Māori women

Tino Rangatirotanga status is being powerfully reclaimed by Māori, challenging othering and researcher knowledge and power, by the development of Kaupapa Māori methodology and methods as outlined in the *Chapter Four: Methodology*. Māori concern with the way Māori, and in particular Māori women, have been ‘other(ed)’ in white-conducted research is legitimate. As Pihama (2001) says:

I will never be convinced that our **tūpuna wāhine** were ‘unclean’, ‘common’, ‘profane’, ‘inferior’, ‘savages’ as ethnography and anthropology has so often portrayed us. I will never be convinced because it does not fit with the knowledge I have of our **tūpuna wāhine**, nor does it fit with the many **Māori women** who daily struggle for the survival of their **whānau, hapū and iwi**. (p. 44, author’s emphases)

In locating and positioning Māori women in this project the question concerns how Indigenous writers position themselves in their multiple subjectivities. I begin with terms that position the event and effects of heterogeneous European empire building in Aotearoa New Zealand, then present a range of views on identity from cosmogony and traditional society, the effects of colonisation and multiple ethnicities, and Indigenous existentialism. Identity connects with this enquiry as it affects notions of self, place in the world, and views about bodies.

Colonialisms and Indigenous existentialism

The position I take in this geography is that that there has been no point dot at which colonisation has ceased and a glorious vista of newness and equality for Māori has emerged. Terms used amongst colleagues are simply ‘colonisation’ and ‘decolonisation’ as effects of colonisation are viewed as ongoing. The struggle for decolonisation or Indigenous existential equality is uneven and there is a social justice mandate to which nursing can and should contribute. So I turn to the literature for a brief overview of how the struggle for equality is constituted, beginning with the colonialisms.

In Gandhi’s (1998) review of postcolonial literature there are two strands: i) the discursive strand which involves ways of knowing and is informed by poststructural critiques of the privileging of Western knowledge, and ii) the materialistic strand informed by Marxism, which contains the view that the marginality of minorities is based on historical, cultural, political, and economic factors. These material factors lead to intersecting oppressions of race, class, and for postcolonial feminism, gender. There are also different terms in postcolonial literature that

reflect different theories. “Post-colonialism” has a hyphen to emphasise decolonisation, which theorists critique as, “the implied separation between colonialism and its aftermath - on the grounds the postcolonial condition is inaugurated with the onset rather than the end of colonial occupation” (Gandhi, 1998, p. 3).

To Indigenous academics, post hyphen colonialism privileges non-Indigenous academics as both Indigenous ways of knowing, such as oral tradition, and current Indigenous concerns are omitted from post-colonial discourse (L. T. Smith, 1999/2005). “Postcolonialism” as a continuous word (no hyphen) and theoretical term in the literature may be argued as demonstrating the ongoing nature of the consequences of occupation so that colonisation is emphasised as not having ended (Gandhi, 1998, p. 3). What Gandhi (1998) points out though, is while postcolonialism may be a way Western academics recognise the knowledges of non-Western “submerged and occluded voices”, the knowledges are still marginal to the West when they may be “central and foundational” to the non-Western world (p. ix). Two further literary terms are “the postcolonial” and “postcolonality” (Gandhi, 1998, p. 3). Gandhi (1998) considers both existential but prefers postcolonality as describing the “condition” (p. 4) the theory of postcolonialism addresses. To bring the condition and the theory together, Mutua and Blue Swadener (2004) argue for a connection between the discursive and materialistic strands so as to connect postcolonality with decolonisation. The connection of the theory of the discursive with the politics of the material (Gandhi, 1998) may be a nursing praxis way to move in the world (A. J. Browne & Smye, 2002).

To Indigenous academics there cannot be post colonialism until the Indigenous past is reclaimed as colonialism is still being enacted through poverty, racism, and other forms of disadvantage (Diaz Soto, 2004; Mikaere, 2011; L. T. Smith, 1999/2005). Voice and power of ‘other’, language, reclaiming epistemologies, and naming injustices told as strategies of resistance to the silences of oppression in Euro-centred epistemologies, bring about the processes of decolonisation. The named injustices powerfully told in the women’s stories in this project might be seen as strategies of resistance to be presented in a critical geography of health and so contribute to the decolonisation project. What is clear is that there are Māori scholars who argue that colonialism is both ongoing and has “new form[s]” (L. T. Smith, 2012, p. 174), sometimes referred to as neocolonialism. Neocolonial discourses in health are defined by Canadian nurses, Browne and Smye (2002), as “new forms of colonial ideology embedded in institutional policies and practices, for example, institutional racism, or racialised discrepancies in access to health care, education or economic opportunities” (p. 31). In that view there is an ongoing requirement for decolonisation, as considered earlier (Ramsden, 2002), at least for

Tauiwi Pākehā. An alternative scholarly Māori view to the decolonisation project is Indigenous existentialism (Hokowhitu, 2010b)

Hokowhitu (2010a) rejects as inauthentic identity the view that being born Indigenous forever equates to being born into subjugation, forever oppressed, under occupation. As an Indigenous to other Indigenous he rejects the colonised/coloniser binary, as by reinforcing the dualist concept its power structures are reinforced. He questions the meaning of decolonisation, and wonders if it is ever possible, preferring instead Indigenous existentialism with its possibilities of choice and responsibility. Indigenous existentialism is “our capacity to ‘be’ in the present, to enjoy the materiality of our situation, to live free of the consciousness of the will to power of another, to live free of occupation” (Hokowhitu, 2010a, p. 224). Recognising choice and responsibility enables Indigenous movement on from an identity and resistances tied to a colonial past. Indigenous existentialism as espoused by Hokowhitu, reminds us that Māori ontological experience is heterogeneous. The risk of Indigenous existentialism as an identity theory informing health care and health policy would be its alignment with a biomedical view of individual lifestyle, so masking neocolonialism.

The research task concerns how the participating Māori women are located and positioned so that colonisation’s othering and marginalisation on the low end of the social gradient of health for disproportionate numbers of Māori is not seen as a permanent state. Rather, suffering disparities is (in)authentic identity. Further discussion on re-presentation and (mis)re-presentation, location and positioning involves identity, which in the words of Te Punga Somerville (2010) may be “a productive or limiting concept depending on the scholar” (p. 41).

Re-presentation of Māori women

How Māori women individually perceive themselves and how others perceived Māori women informs the meaning women attribute to self, relationships with the world, and to bodies, contributing to the experience of being constituted as central in society or as being ‘other’. In a critical theory, the work of Māori scholars is fundamental in mapping the politics of identity. In this section there are four, partially interwoven, identity themes by Māori scholars that are relevant: i) Māori appeals to tradition of cosmogony and whakapapa; ii) effects of colonisation in Māori women’s othering and exoticism, Native Informants, generational identity change, and dual or multiple ethnicity; iii) Māori as Pacific; iv) authentic and (in)authentic identity.

Tradition: Cosmogony and whakapapa

There is a Māori scholarly appeal to ancient myths that serve to locate and position wāhine Māori, to make social order explicit, and as noted earlier, Māori women are central in their whānau, hapū and iwi and in their connection to atua wāhine in their whakapapa cosmogony

(Kahukiwa & Grace, 1991; Mikaere, 2011; Pihama, 2001; Simmonds, 2011). Mikaere (2011) notes the complexity of Māori knowledge in the myths, for example, Papatūānuku as earth mother is atua, tupuna and earth, and Rangi-nui as sky father is atua, tupuna and sky and there is no way to separate those identities. In Māori cosmogony, Mikaere (2011) contends, atua and humans are non-hierarchical, contrasting with the multiple subjectivities of Māori women in the social and historical context of colonisation. As noted in *Chapter One :Introduction* Māori society has been described as democratic and there were chiefs, commoners, slaves, and priestly experts (Keane, 2013). Women may be ariki by virtue of their whakapapa, birth order, or by feats as seen in atua. Mikaere (2011) attributes to whakapapa the inseparable identity of the physical world from that of the spiritual world and dimensions of time: "The logic of whakapapa tells us that in the final analysis, we are our atua and they are us the divisions between past, present and future are indistinct" (pp. 319-320).

'Māori' as a unifying identity is challenged in practice and concept, many preferring 'iwi' (Pihama, 2011). The colonial beginnings of 'Māori', means to Hokowhitu (2010a) a dualist concept given without choice and therefore an (in)authentic identity. Iwi to Rangihau (1975) are the various bones comprising the structure of the Indigenous Peoples of Aotearoa New Zealand and his identity as Ngāi Tūhoe is located in the sacredness of place and the sacred institution of the marae. Hokowhitu (2010a) argues that identities change and that appeals to nationalism and 'pure' forms of Indigenous pre-colonial culture are (in)authentic, they "limit and exclude, ... Indigenous cultures were never in stasis" (pp. 216-217). The nationalistic pre-culture appeals, such as to cosmogony, to Hokowhitu, devalue Indigenous existentialism. The effects of colonisation may be negatively conceived, as in othering, or positively as embracing dual (or more) whakapapa.

Effects of colonisation on identity-making

Examples of Hokowhitu (2010a) and identity "never in stasis" may be self-identity changes found by Houkamau (2006) in three different generations of Māori women. Women born in traditional areas before urbanisation from the 1950s reflected their identities positively (Houkamau, 2006). Those born in the assimilation period until the late 1960s reflected their identity with tension, which Houkamau attributed to their experiencing early in life the negative view of others on their being Māori. The third and youngest group born from the 1970s in the renaissance period, highly valued and affirmed their identity as Māori despite ongoing discrimination by Pākehā towards Māori. While Houkamau noted the effects of colonisation on Māori women's self-identity construction, Sutton Beets (2000) looks at a colonial construction re-presenting Māori women as other and exotic.

The construct of Māori women as other and exotic is seen as an example of colonial portrayal of Māori at the intersection of gender and race (Sutton Beets, 2000). As a Māori woman scholar, Sutton Beets (2000) critiqued the images of Māori women in early twentieth century postcards as being for the voyeuristic male gaze contrasting with traditional Māori self identity. In an era of postcard popularity, nine million cards were posted in 1909, Sutton Beets (2000) argues that exotic poses of innocence against virgin bush had underlying themes of exoticism, sexual availability, and primitivism and positioned Māori women as ‘other’ contributing to racist and sexist attitudes (Sutton Beets, 2000, p. 17). Contributions to an understanding of racist and sexist attitudes in identity construction of Māori women, such as Sutton Beets’ work, informs places and spaces in a geography of health.

The construction of study participants and the expectations of and on Māori in the academy is to (mis) re-present Māori, in bell hook’s often quoted phrase, as “Native Informants”, constantly available to the dominant group (Pihama, 2001). The ethics of participants being cast in the role of speaking for all Māori is discussed later. Webber (2008) with dual whakapapa describes her experiences in the academy as being considered an approachable Māori by Tauwiwi and not Māori enough by Māori. Māori scholars with both Māori and Tauwiwi heritage inform the location and positioning of Māori women and whakapapa is a central theme of authenticity of Māori identity (Houkamau, 2006; Moeke-Maxwell, 2005; Pihama, 2011; Simmonds, 2011; Webber, 2008). The complexity and possibility is articulated by Moeke-Maxwell (2005):

The bi/multiracial woman lives with the ambiguity created in her dual cultural positioning in a way which exceeds the Maori Pakeha/Other divide, thus producing not a “superior” identity, but an identity that constantly negotiates itself in relation to her unique historical circumstances as native/colonial, colonized/colonizer and Maori/Pakeha/Other. (p. 503)

Pihama (2001) whose father is Te Ātiawa and mother Pākehā calls whakapapa “...our cultural genealogical template” (2011, para 2) and reiterates from the experiences of her Māori/Chinese friends, whose identity as Māori is not at times acknowledged by Māori, that it is whakapapa and not looks that identifies Māori. Webber (2008) of Ngāti Kahu, Ngāti Hau, (both Ngā Puhī), Ngāti Whakaaue (Te Arawa) and Scottish and Irish whakapapa, recalls the feeling of being called “half-caste” as a child playing (p. 9). To her in the taunt was the notion of “in-between-ness” of not being truly Māori or Pākehā, rather than the state of being both Māori and Pākehā (Webber, 2008, p. 9). Stewart-Harawira (2007) of Waitaha and northern Scots descent, both of which she views as strongly matriarchal, self identifies as “neither hybrid nor of multiple subjectivities. I am simply both” (p. 124). There are further aspects of heterogeneity in identity

construction relevant to the location and positioning of women in this study, that is the relationship of Māori and Pacific and Indigeneity.

Māori as Pacific

Te Punga Somerville (2010) contends that for Māori, being Pacific and migrating preceded Indigeneity and identity as 'Māori', reflecting Mikaere's (2011) description of the complexity of Māori knowledge. In Māori thought, identity, without contradiction, is both tied to the land (maunga, awa/moana, kainga, marae, tūrangawaewae) as Indigenous, always been there, and to the water through migration from Hawaiki (waka) (Te Punga Somerville, 2010). The dominant discourse has been Indigeneity, emphasising land and associated resources, and connecting with Indigenous in other First World countries. For Māori traveling to the Pacific there is the sense of returning to the beginning, to home. An examination of the impact of Europeans on the health of Indigenous Peoples, including in North America, Polynesia, and Aotearoa New Zealand, has revealed that specific European policies disrupted the social organisation of, and between Peoples (Kunitz, 1994). Te Punga Somerville (2010) speaks to the materiality of Māori women participants in this study in her inclusivity of identity construction.

Māori identity: Authenticity versus (in)authenticity

It is for Māori as Indigenous to interpret the detail of the social construction of authentic and (in)authentic identities, representation and (mis)re-presentation in Indigenous facticity. A local to global perspective on identity is given by Stewart-Harawira (2007) who calls for a new way of "being in the world" (p. 125), avoiding both essentialism and romanticising of the past. Indigenous women are both marginalised and "gynocentric-able"(p. 126) to link both the spiritual and political. Concern for the effects on the globe of the "ruthless greed and ambition" (p. 134) of the new imperialism, Stewart-Harawira (2007) calls for a new way of relating between self and other based on the wisdom of her Waitaha matriarchs and the sacredness and connectedness of all things. Indigenous feminism's decolonisation process is to "deeply embrace the Other, who is after all, the Elders teach us, Ourselves" (Stewart-Harawira, 2007, p. 136). Te Punga Somerville (2010) asks, "How can we find ways to recognise those complex histories of movement, migration and so on that characterize the Māori diaspora?" (p. 53). Thinking more locally, and emphasising whakapapa, exclusivism in identity construction by Māori of Māori is challenged by Pihama (2011): "Such racism within our own can not be tolerated on any level. It must be challenged for the colonial thinking that it is" (para.2).

Māori scholars various emphases inform the locating and positioning of Māori women for this project. Houkamau (2006) concludes Māori identity is "the person's unique interpretation of what it means to be Māori which reflects their own social background, relationships and circumstances" (p. 23). As a critical enquiry into disparities experienced by Māori women,

Hokowhitu's (2010b) pertinently questions: "How do Indigenous peoples interpret authenticity and, further, what are the inauthentic identities Indigenous peoples have tethered themselves to in the unsteady waters since colonisation?" (p. 13). Identities tethered to disparities are critiqued in the re-presenting of Māori women in this research in a self and other embrace.

Concluding the mapping

Mapping the theoretical terrain has drawn contour lines and plotted locations and positions to enable a critical view of the influences from the stories of urban Māori women on their health and health care engagement. The theoretical terrain comprises a geography of health, the location and positioning of myself as nurse and researcher, and of urban Māori women, the focus of this enquiry. Geographies of health as a critical theory are both material and discursive and allow for physical and metaphorical understandings of place and space, networks and connections contributing or not to health and health care engagement. The depth and complexity of the Māori concept of whakapapa, understandings of marginalities and resistances that change the place of most power, geographies of women's health, and therapeutic landscapes as ideal, as goal have been mapped into the geographies of health section.

Knowledge generation involves power, which in a critical theory needs to be overtly acknowledged. In a critical geography, researcher power is made explicit by researcher location and positioning, and in researcher representation of the topic of health care and health care engagement. As a Pākehā nurse/researcher in an historically, and continuing, contested research space, I locate and position myself through powerful discourses of representation, whiteness and privilege, imperialism and colonialism, one nation and becoming a native, white racial dualism and white guilt. The processes of decolonisation, at least for those who share my positioning and location in Aotearoa New Zealand, are through cultural safety. It involves beginning to understand how we may be seen for our Pākehā-ness in the eyes of Māori women, our negative and positive role as power bearers in nursing practice with Māori women, and as we work to address inequities in health for Māori women.

The different theories of colonialisms and Indigenous existentialism contribute to an understanding of the location and position of Māori women. The powerful processes of colonisation have disrupted and affected identity making and created inequities affecting health and health care engagement. The themes in identity-making by Māori scholars are whakapapa and inclusivity and constant change, and Indigenous existentialism, and will be returned to as part of a wider discussion in *Chapter Eight: Discussion*. In the next chapter, the methodology and method are defended as appropriate for this study's aim. Kawa Whakaruruhau categories of difference, power and subjective assessment are shown as appropriate for keeping everyone in

the research process safe, and the research emancipatory in its aim, execution, and outcomes. For difference is not for building walls on the terrain but for creating transformative spaces.

Chapter Four: Methodology

The aim of the study assumes a possible link between the disparities in the morbidity and mortality data of Māori women, and health care engagement (Talamaivao et al., 2010). In this chapter I give reasons for choosing qualitative methodology to meet the stated aim.

“Methodology is an important aspect of knowledge generation” (Thomas, 2000, p. 53), knowledge and its generation processes however, are contestable (L. Brown & Strega, 2005). The method of unstructured interviews is shown to be compatible with the “...principles, theories and values...” (Somekh & Lewin, 2005, p. 347) comprising qualitative methodology. The data is organised by thematic analysis. Mind-maps, reflection and reflexivity helped me to identify themes. Reflection on the data was supported by reflection on my ongoing nursing practice and on literature including Māori fiction and poetry.

Locating my position as the researcher to participants and research site will be my commitment to examine that location and its effect on this research in various and continuous ways (Potts & Brown, 2005). Strengths and weaknesses of the methodology and method, the ethical approach, and rigour of the enquiry are defended. Ethical requirements and keeping participants, research locality, researcher, and sponsoring university safe, has particular significance being a Pākehā researching with Māori in my work place with implications of power and difference. Overall, my intention is that this research addresses issues in the women’s lived experiences of disparities in health and health care engagement. Power and difference are both categories in Aotearoa New Zealand critical nursing theory of Kawa Whakaruruhau, the use of which as a critical theory informing this research methodology I defend below.

Choice of methodology

With the aim formulated my research task was to choose a methodology and corresponding method for a practice issue that was complex and somewhat messy. The quantitative positivist deductive paradigm has importantly observed and given us knowledge of disparities experienced by Māori women in Aotearoa New Zealand, and the rules and systems to duplicate those observations (Gavin, 2008). Knowledge from the positivist paradigm is claimed to be objective knowledge while the researcher maintains a distant location from the subjects of the enquiry. That distance and researcher control intrinsic to the methodology has been critiqued as leading to issues of (mis)representation and oppression through hidden power agendas in knowledge generation failing to give voice to the researched community (L. Brown & Strega, 2005; L. T. Smith, 1999, 2012). The positivist paradigm is often seen as being Eurocentric and often in “... conflict with non-Eurocentric understandings of relationship and community” (L. Brown & Strega, 2005, p. 4). Categories of exceptions, such as Kaupapa Māori and rights-

based research, will be discussed below. Quantitative research needs a statistically determined large number of subjects (Gavin, 2008). In order to explore the diversity of urban Māori women's experiences of health and health care engagement there were women who could be deemed an 'invisible' population to health professionals, health services, and researchers. Both contacting women 'invisible' to mainstream health care and contacting enough in statistically significant numbers would be problematic.

In comparison, qualitative methodology is inductive and evolving, with design being emergent rather than predetermined (Cresswell, 1994; Gavin, 2008). It employs naturalistic observation and researcher - participant interaction to produce complex data that allow descriptions of the stories, analysis, theories and inductive knowledge to emerge (L. Brown & Strega, 2005). The depth of qualitative enquiry, the intensity of analysis requires only a small number of participants, as the researcher subjectively becomes part of the participant's world (Gavin, 2008; Silverman, 2000). Ramsden (2000) promoted qualitative research to "help identify the intangible trust factors in nursing Māori people and others in all the neo-colonial diversity of the 21st Century" (p. 11).

Where qualitative and quantitative methodologies in social sciences are considered binaries, the positivist approach is usually privileged (L. Brown & Strega, 2005). Qualitative, however, differs from quantitative research by "...drawing theory from data, rather than testing theory by data" (Gavin, 2008, p. 236). Critical theory as a qualitative approach holds that no research is value-free, and views reality "as both objective and subjective" (L. Brown & Strega, 2005, p. 9). Physical realities are experienced individually and collectively. Critical theory endeavours to critique and to change social relations that in this study contribute to the disparities in health and health care engagement Māori women experience. To critique is to examine the taken-for-granted, to challenge notions of being. Foucault describes the investigative and transformative nature of critique:

A critique does not consist in saying that things aren't good the way they are. It consists in seeing on what type of assumptions, of familiar notions, of established, unexamined ways of thinking the accepted practices are based.... Criticism consists in uncovering that thought and trying to change it: showing that things are not as obvious as people believe, making it so that what is taken for granted is no longer taken for granted. To do criticism is to make harder those acts which are now too easy. (Foucault, 1994, p. 456)

Critical theory is contextually based and therefore appropriate to an Indigenous and gendered context with influences on health and health care that includes historical, colonial, political, cultural, and socioeconomic influences. “Critical theory must be localized, grounded in the specific meanings, traditions, customs, and community relations that operate in each indigenous setting” (Denzin & Lincoln, 2008, p. 6). To discuss the investigative and transformative possibilities of critical theory, I will refer to the work of Blaikie (2000, 2009) and ‘what’, ‘why’ and ‘how’ questions as a critique process relevant to this research.

To Blaikie (2000), “To *explore* is to attempt to develop ... an understanding of some social phenomenon” (p. 72, author’s emphasis). It involves asking ‘What’ questions: “What might be happening? What people are involved? In what way?” (Blaikie, 2000, p. 83). Understanding in research is informed by insider subjectivities gained by asking ‘why’ questions of the experiences of urban Māori women: “Why is this happening?” (Blaikie, 2000, p. 83). My ethical intent to produce research that benefits the researched and research site is intent for the research to contribute to change, so the ‘how’ question is relevant: “How can it be made to be different?” (Blaikie, 2000, p. 83). With a common understanding of the issue, how will all involved work to address disparities of health and health care engagement for urban Māori women? So the qualitative study design critically asks ‘what’, ‘why’ and ‘how’ to produce knowledge to meet the study aim.

While in qualitative research all knowledge is considered to come from socially constructed viewpoints, the methods the researcher uses may still potentially oppress and further colonise the community being researched (L. Brown & Strega, 2005; L. T. Smith, 2012). Māori and other Indigenous nations have histories of researchers coming into their communities with no commitment to the community, taking what they want, leaving as they had come, and portraying the community to the rest of the world in stereotypical images while collecting personal rewards such as academic acclaim (A. Smith & Pitts, 2007; L. T. Smith, 1999, 2012). This has been a particular critique of the positivist paradigm and the concentration on Western ways of knowing.

Meeting research goals ethically includes the making of recommendations, and reporting back to the research community (Potts & Brown, 2005). Addressing issues of power and difference in the research enables the research to speak to injustice as expressed by the women and as witnessed in my nursing practice. As such, the research is personal, political, and emancipatory (L. Brown & Strega, 2005). Ways to keep everybody safe in this research are discussed below. There is now in Aotearoa New Zealand a rich discourse that challenges assumptions and issues

of power and colonial domination in research and has formulated Indigenous ways of knowing and of creating knowledge (Bevan-Brown, 1998; Bishop, 2008; C. Cunningham, 1998; Durie, 1997a; L. T. Smith, 1999, 2012).

Research methodologies considered by Māori as appropriate for knowledge creating with Māori are Māori-centred and Kaupapa Māori (KM) methodologies (C. Cunningham, 1998); KMHS, the research site, is a Kaupapa Māori service. In KM research, Māori most often lead the team, and Māori generally comprise the majority of the team members. Standards against which the research is measured are Māori, and the control is with Māori. Māori researchers have extended KM research. Quantitative KM research records ethnicity, collects data, analyses statistics enabling disparities between Māori and Tauīwi to be appropriately viewed (Curtis et al., 2005; L. T. Smith, 2012). Kaupapa Hauora Māori methodology for research with Māori health providers offers Māori understandings of wellness, its principles, ethics and spirituality (Wenn, 2007). Mana Wahine methodology critiques the intersection of ethnicity and gender in research with Māori women (Pihama, 2001; Simmonds, 2011). Both Māori-centred and KM research, have Māori as “significant participants” (C. Cunningham, 1998, p. 11).

Māori-centred research as with KM research, demonstrates a commitment to Māori, decolonises research from being about Māori deficits and stereotypes to research that is respectful of Māori, has Māori participation in the process, demonstrates full cognisance of “Māori culture, Māori knowledge and contemporary realities” (Durie, 1997a, p. 11) and produces positive self determined outcomes (Bevan-Brown, 1998; Cram, 1998; L. T. Smith, 1999). For both Māori-centred and KM research the methods and tools are contemporary mainstream and Māori, and the analysis is from a Māori worldview. Māori-centred research differs from KM research in that it may be under mainstream control, measured by mainstream standards, and include Tauīwi researchers (C. Cunningham, 2000). Given researcher and participant positioning, the Māori-driven nursing theory of cultural safety, Kawa Whakaruruhau, offers a critical theoretical approach that is cognisant of KM and Māori-centred research, and deals with the categories of power, difference and subjective assessment.

As qualitative methodology is appropriate for recognising the multiple realities of the participants’ lives, so it is appropriate for recognising the intersection of theories to inform discussion on multiple realities. By reflexivity and reciprocity feminist methodology is emancipatory (Carrier, 1995, 2001) revealing power, privilege and exclusion disparities (Travis & Compton, 2001). Post-colonial feminist nursing

methodology gives women voice by producing knowledge constructed in the social locations of the women that informs action to make health services responsive to the women where they are (Anderson & Kenny McCann, 2002; Truong Donnelly, 2002). Post-colonialism is not in the sense of colonialism being past but in terms of engaging with the injustice and oppression of colonialism present (Brooks, 1997; L. T. Smith, 1999, 1999/2005, 2012). Post-colonial critique challenges power imbalances and racial and cultural stereotypes in those health services and wider society congruent with whiteness, critical geography and cultural safety theories. Overall, the research methodology is legitimately qualitative (Cram, 1998; C. Cunningham, 1998; Durie, 1997a; L. T. Smith, 1999).

Method congruent with qualitative enquiry

The methodology and method need to provide Kawa Whakaruruhau/cultural safety for the participating women, some of whom may have been labeled by health providers: ‘non-responders’, ‘DNA’ (did not attend), or ‘hard to reach’. Women deemed invisible to health professionals, services and researchers, may still be connected to whānau, hapū and iwi. Often the women’s stories related to whānau. The delivering of information is recognised as best given and received by Māori kanohi ki te kanohi (face to face) as in hui (Bevan-Brown, 1998). Qualitative methodology enabled the women’s experiences to be received kanohi ki te kanohi and allowed repeat interviews to follow up, discuss, expand on and confirm emerging themes (Seale, Gobo, Gubrium, & Silverman, 2004).

To hear the women’s stories means accepting an invitation into their own unique world and receiving the telling of their experiences as gift (Potts & Brown, 2005). The gift of their telling requires me to accept in a way that allows for the multiple realities, complexities, and contexts of their lived experiences to be explored in depth and validated as rich data informing the findings. Cultural safety theory as appropriate to me in this research project needs to be inherent in the methodology, in the choosing of appropriate methods, and in the manner in which the gifting is received. I was already coming to the research with subjectivities in my context of being Pākehā with family roots to 1842 and 1871 arrivals to Aotearoa New Zealand, relationships with Māori from my early years, nursing practice relationships, and in particular, subjectivities from relationships within a Māori health provider and marae community. The methodology and method needed to endorse acknowledged researcher subjectivities as legitimate, and the collection of data in this natural setting as appropriate.

When I initially thought of the research site being another marae site, my manager questioned why I wouldn’t consider KMHSS as the location site, as KMHSS often supported research but the results went to mainstream and did not directly benefit our

organisation. It was seen this research could potentially benefit the organisation's practice and service delivery, as the enquiry is a team practice issue about which we endeavour to be proactive and holistic.

Recruiting participants

Recruitment happened in two phases, first with eight then seven participants who all identified as Māori women. For both phases I advertised the study using the *Information Panui* (Appendix 3), firstly at usual marae hui and then with colleagues to marae whānau with whom we engaged in our work. That the women knew me as a nurse at KMHSS assisted recruitment. The participants wanted to help my learning, or said they had agreed as they trusted me, and they identified as having a story to tell. One woman through a change in her personal circumstances at that time did not have a formal second interview. She did, however, confirm the first interview data. One had a follow up interview by phone. Two women chose to be interviewed together in a hui and their individual interview data was extricated from the joint data and returned to them separately in written form. Through a statement in the *Interview Consent Panui* (Appendix 5) I offered participants a CD recording of their own interview if it was exclusive.

The participants were all urban living and had either in their lifetime or in the preceding generations migrated to the city from various traditional and rural areas. They ranged in age from 20 years to mid-fifties and most were mothers. None identified, at least to me, that they were takatāpui, were women who had sex, or were in relationship with women. The participants identified women's health broadly as any health issue a woman may have. Originally, the concept of delay included delay that for whatever reason was their own decision, delay by circumstances, through health provider inaction, and delay inherent in whānau stories of illnesses. Some women at the beginning of the unstructured interviews revealed they did not delay their health care for themselves. But they did identify as having significant stories to tell with the hope of improving health care for others. The initial emphasis on delay³⁸ became stories about health and health care engagement, which both centred and honoured the women's experiences more than the original emphasis on the perception of delay could. Stories covered various time frames and were generational. It was the women's choice to participate and each of their stories was significant, a taonga, and relevant in the study jigsaw.

Unstructured interviews

Interviewing is a routine part of life from the asking of questions and the receiving of answers in informal everyday encounters, to formal and structured organisational events (Fontana &

³⁸ For example, see *Ethics Approval 2008* (Appendix 1), *Ethics Approval 2010* (Appendix 2), and the *Information Panui*, (Appendix 3).

Frey, 2003). Thomas (2000) suggests asking the ‘what’, ‘why’, ‘how’ questions to defend the chosen interviewing method. The ‘what’ is the unstructured interview, and a comparison to structured interviews begins the defense of the method. Structured interviews aim to solicit “...precise data of a codable nature in order to explain behavior within pre-established categories”, while unstructured interviews, are not limited by “a priori categorization” and are suitable for qualitative enquiry (Fontana & Frey, 2003, pp. 74-75). Why? Unstructured interviews allow flexibility and sensitivity to each individual woman and their situation (Patton, 2002). The oral discussion and collective dialogue allows exploration of all the issues around the topic reflecting the personally sensitive nature of women’s health. This form of data collection and validated thematic analysis is an appropriate method for research with Māori (Bevan-Brown, 1998). The researcher’s epistemological position for the breadth of the unstructured interview is explained by Thomas (2000) as “there is no verifiable external reality against which the participants ‘answers’ can or ought to be compared” (p. 64). However, as Fontana and Fey (2003) point out “the nature of the social dynamic of the interview can shape the nature of the knowledge generated” (p. 64). An unstructured interview opens up the topic for discussion and gives voice to the participants, which may be something a participant has not previously experienced.

In considering the ‘how’ of the data collection method (Thomas, 2000), the interviewing process allowed for the women to choose their most convenient venue. Interviews were mostly held privately at KMHSS. Others were held in another marae, participants’ homes, and another Kaupapa Māori work place. Having a choice of venue and time, and a choice of interview individually, with support or in a group, was an endeavour to produce a social dynamic to empower the women during the interview process (Burns & Walker, 2005). The interview commenced with culturally appropriate greetings for the research site setting and for the participants that established connections together with “implicit commitment” (Bishop, 2008, p. 158). Healthy food in line with KMHSS nutrition policy was usually offered during the interview as a demonstration of reciprocity and manaakitanga. Depending on the time of the day, sometimes it was left as koha. The *Information Panui* (Appendix 3), which had been given to intending participants on first contact, was reviewed before obtaining written consent.

Although the interviews were unstructured to allow for flexibility and the emerging of multiple realities, having had the purpose of the research explained verbally and in the *Information Panui* (Appendix 3) it was reasonable to have an expectation of the general areas “...her stories...” (Dyck et al., 2001, p. 183) may cover. However, I had *Interviewing Guidelines* (Appendix 4) as my aide-mémoire for both the process and content of the interview. Research with Australian Aboriginal women on cervical screening by Dyck, et al. (2001) informed the

content area. The power of qualitative methodology and unstructured interviews to explore in depth the stories the women chose as relevant to the topic to tell, unfolded to me from the first interview (Seale et al., 2004).

After the preliminaries the first Interviewee tentatively asked, “It is a health issue when you get your first period?” (Mary, Int. 1). It was an unstructured interview beginning I had not expected, which in this first interview and in each other participants’ interview revealed rich data that contributed to each chapter of the findings. The data concerned the onset of puberty, menstruation, generational influences, body knowledge, whānau care, and health education prenatal, in motherhood, and in health care engagement. For some participants it began life-course telling that as one participant (H) commented, was a reminder to her of the stories she needed to tell her whānau.

The length of most recorded interviews was about an hour, fitted around work schedules or child-care. A few stories were told rapidly, while undertaking household or other tasks. The shortest and only telephone interview was a follow-up eight-minute recording. The longest interview was also a second interview. At its conclusion I wrote:

I just sat in this interview today and said little. I was in another world, a world of sadness and abuse and youth and healing and hope. The length of the interview (02:38:54) was about slow, searching for words at times, and about trauma softly recounted and gradually her advice about how health services should interact with women in her world. I wouldn't have got the important things if I had hurried, stopped any earlier, or given up on her as I had text this am and she had gone to our rendezvous without texting me back. She had not turned up twice for our last appointment, once confirmed 45 minutes and another 120 minutes earlier, and had then responded to my texts by suggesting another time. After concluding today I took her to lunch to ease us back from that deep place and she chose (name of eating place). (Journal, December 12, 2011)

Louise’s spoken reasons for not showing previously were beyond my lived experience. As with health care engagement, other priorities and barriers can present themselves before research interviews. It was the unstructured interview method that allowed the diversity and depth in her story, and in the other participants’ stories to be told and explored. The rich data then needed ordering through analysis.

Thematic analysis

The data generated were analysed to identify themes that enable systematic communication of findings (Boyatzis, 1998). Boyatzis (1998) defines a theme as:

A pattern found in the information that at the minimum describes and organizes possible observations or at the maximum interprets aspects of the phenomenon. A theme may be identified at the manifest level (directly observable in the information) or at the latent level (underlying the phenomenon). The themes may be initially generated inductively from the raw information or generated deductively from theory and prior research. (p. vii)

An example of a common theme identified at the manifest level, inductively generated from the interview data, was that of generational influences: “We were told by our mother, and our mother was told by hers” (Mary, Int. 1). “That was because of my grandmother and what she told me” (Anne, Int. 2). An example of a latent level theme is that all the participants were urban Māori women variously connected or not with their traditional roots in other, mostly rural areas; they were all part of the phenomenon of Māori, and indeed Indigenous, rural to urban migration. The latent theme of loss of land and loss of economic base, and for some, loss of any knowing connection to the land of their forebears, is colonisation. Gavin (2008) further explains the reflective process of thematic analysis.

Critical reflection

To Gavin (2008) thematic analysis is a complex process of reflection of the text for participant and reader that cannot be explained explicitly. Gavin outlines the stages:

- Examine the data for the emergent themes
- Identify all data that relates to these themes
- Combine related patterns into sub-themes, units derived from patterns that can be brought together
- Check that the sub-themes are truly representative, by referring back to the data and/or the participants or checking with a co-researcher
- Identify the argument for choosing the themes, possibly by relating to the literature. In this way the reader can identify the process by which the researcher has developed the themes. (pp. 280-281)

During the interviews I used a mind map mostly mapping around ‘health’, ‘delay’, and ‘health services’ and filled them in further while reflecting post-interview and listening to the recorded interview. Two examples of mind maps will be given below. The selected words reflect the research aim, and the assumption I had made that ‘delay’ was a health care engagement

perception by health professionals. I transcribed or checked transcribed data with the recording to ensure “it was true to its original nature” (Braun & Clarke, 2006, p. 88). In this way I familiarised myself with the data and selected further code words. The mind maps enabled me to ‘see’ and connect patterns, or potential themes from each code. In the second interview I reviewed the first interview and discussed with each woman how I saw or interpreted their stories and together we further explored their meanings.

I have reflected critically on the interviews (Fook & Gardner, 2007), looked at my own reactions to the stories, and at the women’s reactions to the process and to the stories when they read them back (Barnard, 1990). This enabled me to analyse emerging themes from the interviews (J. Browne, 2004). As herising (2005) says, “By situating and contextualizing ourselves, and ourselves in relation to the subjects of our research, our work can provide strategies for counter-narratives and oppositional politics” (p. 135). I recognised similarities in my research and nursing reflection to the manner Ana Maria Araújo Freire (2007/2012) described of her husband Paulo Freire’s work: “ an uninterrupted practice-theory-practice movement ” (p. 361). For me at that time it was reflecting on practice, reflecting on data and literature, and taking that reflection back to my nursing practice and to discussion about practice with colleagues, and then to my writing. While scholarly literature iteratively informed the identification of themes (Gavin, 2008), Māori authors of other genre also aided my critical reflection process, as in the following examples.

In Sturm's (2006) short story *Mollie Murphy's vacuum cleaner*, I reflected on the different worlds of Māori and Pākehā. Mollie’s mother “listened to the [Pākehā] rellies and the [Māori] cuzzies with equal respect and then quietly made up her own mind” (Sturm, 2006, p. 91), a description of personal agency in negotiating difference. Action also depended on whom one was with. From Sturm’s (1996) intimate poem, “Maori to Pakeha: *for Peter*” my reflections concerned whom and what Māori may see, when they see Pākehā? Difference, colonisers, aliens straying into “brown country”? (Sturm, 1996, pp. 50-51). In *Mutuwhenua: The moon sleeps* (Grace, 1978) I reflected on the richness in being open to understanding difference encountered in relationships with Māori. “I know it's possible to be close, and to love, and that even with differences you can be open to knowing” (p. 152). Events in our history as a nation may have different and ongoing effects for Māori from Tauwiwi/Pākehā participating as in Grace’s (2004) novel *Tu*. Tauwiwi/Pākehā and Māori who were equals together in battle, post-war were not. It resonated with whiteness theory and the inherent power and privilege in being white, that once need was past, reasserted itself in the ongoing effects of domination and colonisation. I wondered about the contribution to Māori health and health care

engagement of the sense of no gain in Māori equality with Pākehā/Tauīwi through sacrifices in war? Did it impact Māori health and health care engagement through stereotype threat, cultural memories, bodily remembering?

Grace's stories further reflected participants' stories such as the intergenerational life course effects of punishment for speaking Māori at school in Grace's (1998) *Baby No-Eyes*, and subsequent loss of language, names, stories, knowledges, land and life. Participants' stories of parents and grandparents patiently working hard and silently, not wanting their children to go through the pain they had experienced were reflected in Grace's fiction. The pain resonated with Mikaere's (2011) theory on the interwoven whakapapa of land, language and health. The next examples of processes supporting critical reflection in this study are those of mind mapping.

Mind mapping example from Shar's stories

This section from the mind map of Shar's stories descends from the [Health Services] code.

[Health Services]

[POWERLESSNESS]

GP :

- Feeling that GP not listening to her- irritated with him –doesn't want to see that GP again
- Different doctors not listening to her
- Wants doctor to have relationship with/know history
- Doesn't like locums –no hx, no relationship, only read what's on screen.

Felt rushed:

- \$15 for 2 mins consult
- Didn't get asthma medication she asked for
- Had to use child's inhaler for own asthma
- Had four things for self and child – own chest pain, own anxiety px [prescription], baby's conjunctivitis px, own asthma px. None attended to properly or at all.

Worry:

- Worried about baby (has been in hospital) - before own health
- Sense that some doctors from other countries not competent
- After-Hours a number of times. Cost of After-Hours GP cf Time taken 'one week' in ED hospital (other child responsibilities)

- Some okay. Others say, 'Fine' [about sick child]. [Doctors and nurses] should listen [to mothers]. Mothers know their own children. Would like health professionals to take more notice [of mothers]

I discussed my interpretations of the first interview with Shar in the second interview, a reflexive process (Lather, 1991). Shar expressed further outrage with subsequent attempts at accessing appropriate health care for herself and her children. I added to [POWERLESSNESS]:

- Unhappy with GP in m/c but didn't say anything or "I would have made a fool of myself" (Shar, Int. 2).

On the transcripts I used highlighters for the next stage to identify all the data related to the theme of powerlessness. Highlighting text enabled me to keep the context of the emerging themes while coding the data (Braun & Clarke, 2006). I highlighted green over this section for Kawa Whakaruruhau. On my guide for Kawa Whakaruruhau I had made notes, "analysis of structures of power in settings and systems, practitioner responsible, safety subjective, social justice/human rights". I used highlighter pink for whiteness theory. On my guide for whiteness theory, I had noted, 'Social construction of racial categories', power and privilege in health system, health professionals'.

I began reflecting on patterns and potential themes. Powerlessness in privileged health care spaces, powerlessness in poverty, possible overlay of racism, lack of support and/or knowledge to complain, human right's violation, health at risk. Disrupted networks, for example, from a medical centre to a pharmacy for needed medication, and disrupted trust in health care provider through disregard of her cultural safety, her Indigenous right to the provision of Kawa Whakaruruhau. As I connected these potential themes with those of other participants, I further integrated theory by reflecting on them as a landscape where spaces and places and their networks and connections impacted health and health care for women and their whānau. I checked back across the whole data set again and again for coherence and accuracy, choosing clear examples of the themes (Braun & Clarke, 2006). The different thematic levels to which this example contributed are presented in *Chapter Six*:

6. *Contested landscapes: Space, place, networks and connection*

Power relations and spatiality

Issues of power and poverty.

Mind mapping example from Pam's stories

One section of the mind map of Pam's stories descends from the [Body] code, a theme common across all participants. In Pam's first interview the connecting highlighted words under this theme were: [Body], [Generational change], [Health information access], [Vision for the future].

Body:

- Doesn't talk to her Mother or whānau about her body or health "All that kind of stuff doesn't get talked about in our family" (Pam, Int.1). Only kids' health
- Pam's Mother hadn't talked to her about her body
- Period 9-10y "Ugh, something's wrong with me. I'm bleeding" (Pam, Int. 1)
- "I'm all right as long as my kids' all right" (Pam, Int.1) - Children first before self/care of own body or health.

Generational change:

- Is going to be talking to her babies [about their bodies]
- Wants her children to be able to come and talk to her about anything
- Children's questions Pam's stuck on:
 1. How does the baby get born? Puku?
 2. Where does the baby come from?
- Doesn't know what's appropriate for age so doesn't talk to the kids about the two questions.

Health Information access:

- Puberty at Intermediate "That's when I started to find out about everything, 'Oh, wow, mm'" (Pam, Int.1).
- No internet access
- Has library card - use 1x month. Not had books out about bodies
- No antenatal education over a number of pregnancies from age 15y - linked to Health Services Code.

Vision for the future:

- Happy, safe, good education, know they're fully loved, have a home, a whole whānau to go to
- Asks her children what they want to be

- Eldest son wants to be a doctor/builder
- Eldest daughter wants to be a MacDonald's girl - Pam says "own MacDonalds"
- Pam wants them to have 21st birthdays (i.e. not have babies as early as Pam and their father had)
- 'Never know what happens out there'.

The body theme linked with other participants as [generational silence] about bodies, and through processes described above contributed to the different theme levels in:

5. *A whakapapa of health*

Interwoven whakapapa: Land, language and health

Preparing growing bodies: "I was never learnt any of that"

[Generational change], [Health information access], [Vision for the future] contributed to different theme levels in *Chapter Seven*:

7. *Therapeutic landscapes: Remembering and imagining an ideal*

Remembering and imagining: Mapping the future

Remembering and imagining: "For my kids" and

Bodies as landscape: "I'd be interested in learning about ... both bodies."

Pam's experience of mid-teen parenthood and no antenatal education in [Health Information Access] linked to [Health Services] contributed to the different theme levels in *Chapter Six*:

6. *Contested landscapes: Space, place, networks and connection*

Power relations and spatiality

Systemic exclusions: "I never had any of that support never."

Now to return to consider reflexivity more fully as it has been an ongoing part of interpretive and analytical process.

Reflexivity

The process of reflexivity as the core of critique in critical theory is rooted in Ancient Greek philosophy and more recently stemming from Rene Descarte's "I think, therefore I am" (Reflexivity, 2002). Reflexivity becomes a seed of knowledge, when consciously being able to reflect back on one's own conscience, one knows with some certainty ones own existence. In a discussion on Bourdieu's theory of reflexivity, Wacquant (1992) associates its derivation with

“*Re-flectere*... [meaning]... to bend back” (p. 36). The notion of the bending back from participant to researcher the effects of the study and researcher on the participants is common to social science theorists in their production of knowledge (Reflexivity, 2002). Bourdieu (Wacquant, 1992) includes the researcher as object of reflexivity, and, specifically to him, the whole process of sociological research as “epistemic reflexivity [because] ...it informs a conception of the craft of research designed to strengthen its epistemological moorings”(p. 45). The reciprocity in reflexivity is non-hierarchical, has a place for feelings, gives and receives information and knowledge, and is emancipatory in outcome (Carryer, 1995). Lather (1991) uses the term “research as praxis” to describe the strength and partnership focus of feminist methodology when through “reciprocal reflexivity” it consciously enables the researched to gain understanding of their situations and to work for change (p. 57). A personal problem, such as difficulty with health care engagement, becomes linked to the political allocation and organisation of resources, a societal problem (Gavin, 2008; Lather, 1991).

Reciprocal reflexivity was part of my research process from the conception of the study. Reflexivity began as a practice issue bouncing back from Māori women, colleagues, other professionals within and external to our service. My response to explore a nursing practice issue, went out and came back, went out and back, out and back, multiple sharings and shapings of the research process, the ‘producing knowledge’ process. I will illustrate reciprocal reflexivity from different phases in the research process.

While advertising the research to gain support to recruit, I presented the *Information Panui* (Appendix 3) at a regular hui to Māori nurses. I noted three different responses. The first was to seek required participant profile clarification, a practical support response. I responded by clarifying with the *Information Panui*. The second response was being “asked if she was one of the women, what would there be in it for her. There had been so much research and what difference had it made” (Journal, February 12, 2009). I reflected on the response as one that was legitimately concerned with protecting potential participants (including, and particularly, the responder) who as Indigenous Peoples have been over exposed to, and misrepresented by, research and researchers without personal benefit for themselves as participants (Duvnjak & Fraser, 2013). This second response could be called a ‘research-weary’ or ‘research-guarded’ response.

The third response was a painful and recent identification with the research topic, as the responder quietly and tearfully shared her whānau story in the hui, illustrating emotionally and verbally her understanding of the research aim, and her support for the research. There was informing reflexivity in each of the responses and the reflexivity of the third affected us all, and

our sharing of feelings was non-hierarchical. In time, other Māori women responded to an invitation to participate in the study because they also identified with the topic, having an individual or whānau story to tell, the bending back of identification with the research aim. ‘Anne’, a Māori woman I spoke to about the study whom I knew had good connections in the Māori community locally and further afield, is an example. I was hopeful Anne might be able to advertise the study:

I told Anne about the research on her way out after a smear. I talk now about women being ready to tell their stories. I thought she would be able to pass it on. “Oh, does this count?” she said, and then told me what her delay had been and asked if it met the criteria. I agreed, showed her the *Information Panui* and she cheerfully said she would be interviewed. We arranged it and another rich story (Journal, May 6, 2009)

In the recruitment phase Anne quickly identified with the research aim and briefly checked her story outline with me in a reflexive process. After Anne’s second interview I noted on the mind map “Interviewee said off-tape that I had captured the emotion of the stories in the first interview”. Anne’s comment was based on the experience of the first interview, receiving and perusing the CD and transcript of that interview, our review of the first interview in the second interview and a discussion of each other’s interpretations of her stories and responses to them. Reflexivity was the process of checking with the participant the subjectivities I as researcher brought to the research project. It was also the process of checking my general thinking with others whose support I desired, such as other urban Māori women whom the research could be seen to vicariously represent. The process of reflexivity will be employed to defend researcher location.

Defense of location

In a practice issue enquiry where women may be perceived to be marginalised through for whatever reason not accessing “social goods” such as a health appointment (Hurley, 2007, p. 162), the relationship between the researcher and the researched is highlighted to ensure social justice is reflected in the process and outcome (L. Brown & Strega, 2005). The location of the researcher needs to be both acknowledged and examined through the processes of reflexivity throughout the research process to expose the subtleties of power relations of which the researcher is a part. The research participants were Māori women who may have been, and could again be, recipients of my nursing services. To justify my position I will consider the three questions posed by Spoonley (1999) on cross-cultural research that are ethically relevant: “What is the purpose of the research? Am I the right person to be doing it? Will the research be compromised?” (p. 53).

Influences on Māori women's health and health care engagement may potentially compromise their wellbeing contributing to amenable mortality. The research purpose is also to fulfill my academic requirements. While the ideal for research is 'by Māori, for Māori' (L. T. Smith, 1999, 2012), Tauīwi nurses are employed and supported by Māori to work with Māori to achieve Māori aspirations for whānau, hapū, and iwi. Māori nurses account for seven per cent of the Aotearoa New Zealand nursing workforce, and 56 per cent of nurses employed by Māori health providers identify as Māori (Nursing Council of New Zealand, 2014). The percentage of Tauīwi nurses employed by Māori health providers is significant. Ramsden (2000) acknowledged that Māori health providers endeavour to practise tino rangatiratanga even if they did not have the Māori health professionals. Cultural safety theory is for the Tauīwi health professional in the Māori health provider, so that together with shared understandings of power and legitimacy whānau receive a professional and culturally safe service. It is reasonable to argue, then, that in partnership, (Spoonley, 1999) Tauīwi nurses employed by Māori are in a position to legitimately "research as praxis" (Lather, 1991, p. 57) with Māori when research seeks to legitimise issues of the community (Silverman, 2000).

A Tauīwi nurse in a Māori setting is an outsider by virtue of ethnicity, but as part of the work community may be seen as a whānau insider, but as a researcher in that setting, an outsider again (L. T. Smith, 1999, 2012). Narayan (1997) proposes a move from insider/outsider positioning, as researcher and researched have multiple and constantly changing identities and power relationships in various and changing interrelated communities:

Factors such as education, gender, sexual orientation, class, race, or sheer duration of contacts may at different times outweigh the cultural identity we associate with insider or outsider status. Instead what we must focus our attention on is the quality of relations with the people we represent in our texts: are they viewed as mere fodder for professionally self-serving statements about a generalized other, or are they accepted as subjects with voices, views and dilemmas –people to whom we are bonded through ties of reciprocity and who may be even critical of our professional enterprise. (p. 23)

The qualities in a researcher that Gavin (2008) outlines are a certain frame of mind for naturalistic enquiry that allows the researcher to be a "research instrument" (p. 247), and sensitivity to the data to interpret appropriately. The quality of my relationships in my location as researcher and nurse among work whānau in cultural safety research means as researcher I may well have been the first in the research process to experience change (L. Brown & Strega,

2005). The concluding and making of recommendations and report back is part of ethical and emancipatory research (Potts & Brown, 2005).

At the completion of the first eight participants' interviews and data analysis, a summary report of the study findings to that time was presented to each participant and with a presentation at staff hui, to KMHSS. Report backs are never individual but rather a summary of the study (Gavin, 2008). At the completion of the thesis a summary, including the thesis on-line address, will be given to each participant, and a thesis copy and summative presentation to KMHSS. Recommendations have been made for KMHSS, nursing practice and research.

Strengths and weakness of methodology and method

Foundational to the strength of qualitative methodology and its methods is its essence as a naturalistic enquiry. Other theory of the phenomenon is not a requisite. If a researcher wishes to gain understanding about a phenomenon, qualitative methodology provides the fundamental methods of observation and interpretation to collect data allowing theory to emerge (Gavin, 2008). The theory may give understanding of the phenomenon, offer new perspectives, or provide variables for quantitative enquiry. Qualitative methodology contrasts with models of generalisability and causality as it "actively seeks to examine the subject areas in their entirety and to grapple with the complexity, ambiguity and variability of life" (Parker, 2004, p. 160). Data produced are "textual rather than numerical" (Rudestam & Newton, 2001, p. 95). With natural methods the researcher is able to collect data in a place of the participant's choosing (Gavin, 2008).

The strength of naturalistic enquiry that enabled me to research in my nursing practice site was that I already had existing relationships as a privileged member of the marae whānau. Linda Tuhiwai Smith (2012) suggests the relationship between whānau and methodology is a way that Tauīwi researchers may be involved with research involving Māori. Naturalistic enquiry where partnership between researcher, the researcher's employing Māori community, and participants exists, has the advantage of upholding Māori protocol throughout the enquiry processes. Māori community rights and views, including cultural and intellectual property rights, were respected in the whole qualitative methodology process. The researcher was accountable to the other partners as well as to the university (Massey University, 2014). The acknowledged subjectivities of the researcher are part of the process. Trustworthiness and credibility in relationships are more the focus than validity and reliability and data are rich in their description and depth, providing a vehicle of expression for the participant and with which the reader importantly interacts (Gavin, 2008).

However, there could be a danger of uncritically describing a social discourse adopted by an interviewee rather than of critiquing data from a wider view (Saukko, 2008). An oversimplified description could reinforce stereotypes, even academic ones. For Saukko (2008), a difficulty for the methodology occurs when enquiry of a phenomenon uncovers imaginary and individual resistances that do nothing to alter the structures of power, that is, do not offer real resistances to societal inequities. The methodology may fail to leave space for the experience to critique the context that gave it shape. Attaching a localised phenomenon to wider societal issues may “reduce the local experiences to props for social theories” (Saukko, 2008, p. 460). The strengths of the methodology for Saukko (2008) are when multiple perspectives are openly explored, where global informs local and local informs global potentially inaugurating “more inclusive and multidimensional political responses” (p. 461).

The methodology and method is also problematic at the planning and data collection phases with specificity about study scope and extent (Llewellyn, Sullivan, & Minichiello, 2004), which in this study involved ongoing communication and trust between researcher and supporting employer and colleagues. They had given their support and were involved in recruitment. They, too, had a responsibility to ensure the processes and outcome as undertaken by the researcher and supervised by the university were safe for the participants, marae, their own credibility as supporters and Māori women, and for Māori women generally. Lack of specificity had the potential for supporters own interpretation to have influenced recruitment when they were informing potential participants. Another factor is the subjectivity of naturalistic enquiry means an exact replica of the qualitative study is impossible. Data produced would vary with different researchers and their subjectivities, different research sites and participants, or different times and places. However, a similar enquiry may add to the field of knowledge. I will now review the ethical concerns of the research.

Ethics

Ethical research is designed from the participants’ view point to not only do no harm but to also aspire to benefit the participants by doing good (L. Brown & Strega, 2005; Gavin, 2008; Piper & Simons, 2005). Gavin (2008) outlines four main ethical concerns for keeping the participants, research organisation, and researcher safe and in this project the reputations of the profession of nursing and Massey University: voluntary participation, informed consent, confidentiality, and the person’s right to service. A fifth and equal concern is cultural safety, Kawa Whakaruruhau.

Voluntary participation is of particular concern in this research project conducted in the researcher’s place of work. There is a potential conflict of interest considering the participants may have been, or in the future could be, recipients of my nursing care (Wilson, personal

communication, September 6, 2007). Strategies to deal with the potential conflict were considered with my line manager and team colleagues. It was decided the usual referral process, with the participant's consent, would apply. Similarly, if a complaint were to arise during interview about any of our services, the usual complaint procedure outlined in written form and given to every whānau registering with our service, would also apply.

Further, through power differentials of whiteness/ethnicity, education, profession, socioeconomic status, and age participants could be at risk of feeling coerced. Having Kawa Whakaruruhau/cultural safety theory inform the methodology was a foundational ethical strategy for this project. Contacts for any participants with concerns about the research were on the *Information Panui* (Appendix 3). To ensure participation was voluntary, distance was planned between the researcher and the participants in the recruiting process.

The *Information Panui* (Appendix 3) informed self-identified participants to contact the study organisation supervisor, my line manager, whose name and contact details were included. All effort, including through researcher reflexivity, was made to ensure there was no coercion deliberately or inadvertently by myself or by other staff who had access to potential participants (Gavin, 2008). During the process I often thought of L.T. Smith's (1999) comment that a project was both harder and easier when one was researching in one's own community. The first participant heard of the research and thought of 'her story' and came straight to the nurse clinic, "You know about that, ...you are doing...". My efforts at distance by encouraging potential participants to arrange times and dates with my organisation supervisor/line manager never worked. Another 'distance' strategy was to allow at least a week between giving information about the research and when the interview was scheduled so that the potential participant could reflect and consider withdrawing. That didn't always work as the nearest mutually available day was sometimes naturally, and firmly, requested.

There was no reward of money or of kind for participants, nor was any service denied any woman by not participating. The women were advised they could withdraw at any time if they felt uncomfortable about the information they had revealed about themselves or for any other reason (Gavin, 2008), up until the participant had verified the written interview copy at the second interview. If they had withdrawn up to that stage, their contribution would have been destroyed or returned to them if they had wished.

The second ethical concern of informed consent is "those interviewed ... should give their permission in full knowledge of the purpose of the research and the consequences of them taking part" (Piper & Simons, 2005, p. 56). The Health Research Council (2002/2005) advises

consent to be in writing. Informed consent includes participants not being put in a situation of harm that could be physical, psychological (Gavin, 2008), or cultural (L. T. Smith, 1999, 2012). To ensure the information was set out in terms the participants could understand, the *Information Panui* (Appendix 3), *Consent Form* (Appendix 5), and *Interview Guidelines* (Appendix 4) were reviewed by my colleagues: manager, community health workers, and nurses, Māori women in my work place. At each participant's first interview the consent form was signed and all consents and data were kept safely. Consent included consent to have the interview recorded.

The third ethical concern was confidentiality and privacy. This project was reviewed by the Health and Disability Central Regional Ethics Committee (Appendix 1 & 2) as required in Aotearoa New Zealand to ensure the proposal is sound and appropriate for the practice issue and to protect the interests of participants (Health Research Council, 2002/2005 ; Piper & Simons, 2005). The research complies with the Health Information Privacy Code 1994 ("Health Information Privacy Code 1994," 2008). No identifying information was available to anyone not directly involved with the study. I did not include identifiers such as iwi or place names, and I asked each participant to choose a 'research' name; confidentiality was most important for most. Stories are more personal with a name than a number or other such researcher-chosen identifier. Most may have chosen a name that had some meaning to them. One chose a letter of the alphabet. There would be a place for some to tell their stories with their own names, but that would have been a different project. I conducted the interviews and two transcribers outside the organisation, who had signed confidentiality agreements, assisted with transcribing in the first phase.

The fourth ethical concern is a woman's right to appropriate service. There are possible psychological risks if discussing a difficult aspect of the participant's health care, or that of their whānau, causes distress (Patton, 2002). We had discussed the possibility of referral or follow-up from identified issues at our team hui before recruitment began. No distress necessitated terminating an interview. Referral for follow up by another nurse, community health worker or Māori counselor, or referral to their general practitioner, was available to participants. Gavin, (2008) advises researchers should recognise their limitations. The roles of researcher and practitioner should not be confused or conflicted and the researcher cannot ethically take on another role in the middle of the interview. The *Information Panui* (Appendix 3) and *Consent Form* (Appendix 5) included information about seeking their permission for referral. Overall, Gavin's "rule of thumb" concerning participant comfort is, "to ensure that participants leave the study in the same state or better than when they entered it" (p. 34). This is how three women felt about their participation: "I thought it was a quite a rewarding experience.... a really good

summary. I thought, ‘Yeah, that’s me’. So I was quite pleased with it actually ... I’ve really enjoyed being part of this, Beverley” (Ani, Int. 2).

In her second interview three months after the first, Angel calls it ‘our study’:

I felt that within myself I’ve grown stronger and have a bit more positive outlook and I think having that faith to get me by every day, yeah. And I think without faith I wouldn’t be able to talk about everything in our study, feeling like I’ve done something good for somebody else, where they could reach out. (Int. 2)

Similarly in her second interview, Dolores expresses her feelings about her participation:

“Thank you, because I quite enjoyed this. It was really good” (Int. 2).

The fifth ethical concern is the cultural safety of the participants from the conception of the enquiry to the report back and disseminating of the findings. Discussion from inception with my team colleagues and culturally appropriate processes are noted above. In researching with Māori the researcher worked in collaboration with KMHSS as research site, which in turn has relations both with their whānau, hapū and iwi, and with a network of organisations and other service providers locally and nationally to inform the research process (Hurley, 2007). Hurley (2007) emphasises “Collaborative activity of necessity brings with it critical reflection and absolutely requires the methodological formalizing of reflexivity” (p. 163) for the researcher to be aware of power influences. Re-presentation of the participants as discussed in *Chapter Three: Mapping the Theoretical Terrain* is an ethical issue for continuous reflection. The potential is there for interests outside of the research community to see the research participants in stereotypical ways or as speaking for “many...they are forced into a position of tokenism by being made ‘representative’ of the whole, in order to take the opportunity to speak the issues of the many” (Hurley, 2007, p. 164). Hurley (2007) argues that this tokenism disallows the diversity of experience and location of others in the social group from being acknowledged.

Working with a Māori health provider is about reflecting on and confronting injustice and oppression for people located on the margins (Brown & Strega, 2005). To ethically research in this environment means being committed to an active role in social change. This requires from the researcher ethical reflective practice throughout the process and beyond that is purposeful and political in promoting and enabling social justice at the personal and societal levels. Being part of the community is having ongoing commitment to that community. Ways of ethically being in the world and ways of ethically knowing and generating that knowledge concern

questions of ontology and epistemology. It is also being aware of both of one's own capacity to oppress and of one's capacity to act and alter the relations of oppression.

Research rigour

Rigour (2014) is "the quality of being extremely thorough and careful" and I have endeavoured to make transparent my systematic approach, acknowledging my research relationships to the research, research site, colleagues, and participants as a group (Rudestam & Newton, 2001). Significant persons have informed the process and the knowledge generation. I appreciate the support provided by my supervisors as experienced researchers and teachers who understood the journey, and aided my reflection by challenging, encouraging reframing, or informing assumptions and processes. Their guidance contributed to the rigour of the enquiry, for example, promoting the safety of participants and research site, the university and researcher, and in the knowledge generated. As a peer review I presented *Research as practice: Pākehā nurse, Māori women and ethics* at the 2009 New Zealand Nurses Organisation's Nursing Research Conference. Ethics committee review was noted above, as have collegial discussions from inception, and processes of returning data and the first phase summary report to the women. (Twelve colleagues read the draft before the final report was produced and presented at staff hui).

I have defended how I chose qualitative methodology and the unstructured interview method as congruent with the research aim, and demonstrated thoroughness and care in the interview process. L.T. Smith (2012) says that, "What makes 'ideas' real is the system of knowledge, the formations of culture, and the relations of power in which these concepts are located (p. 50). In the above chapter I have endeavoured, with quotes from my journal and from the data, to make transparent the interpretation of the women's stories and the ways the ideas became systems of knowledge, cognisant of power relations and cultural safety. The use of quotes in the findings chapters has the purpose of validating conclusions drawn. The *Literature Review* places this work in the literature and *Mapping the theoretical terrain* in the realm of ideas. As I familiarised myself with each interview and reflected thoroughly during the data collection process, the multiple realities of the fifteen participants provided the depth and breadth of data to adequately meet the theoretical demands of the aim of the enquiry (Braun & Clarke, 2006). Rudestam and Newton (2001) describe theoretical saturation as "gathering data until no new relevant data are discovered regarding a category and until the categories are well developed and validated" (p. 93). Stories chosen by the urban Māori women participants with an age-range of over thirty-five years described commonalities and different life trajectories and provided rich data iteratively informing and confirming knowledge being generated until

theoretical saturation was achieved. A participant read draft findings and discussion chapters. Concluding processes noted above contribute to rigour.

Conclusion

I have described how knowledge has been generated from the aim. The methodology is legitimately qualitative informed by the critical theory of cultural safety in nursing education and practice in light of difference and power inherent in the project as Pākehā nurse and Māori women. It is cognisant of other methodologies and theories Māori researchers engage to generate Māori knowledge. The method of an unstructured interview, participant review, then beginning analysis together in a follow-up interview has been critiqued with the ethical framework of volunteer participation, informed consent, confidentiality and privacy, and cultural safety. The processes of critical reflection and reflexivity have been demonstrated and the rigour of the research defended. With literature review, theoretical mapping and methodology defense established, the next three chapters present the findings beginning with generational influences on current health and health care engagement.

Chapter Five: Generational influences and landscape:

A whakapapa of health

Landscapes tell of the past; the influences of preceding generations imprinted on landscape present such as the generational influences in the women's stories on their whakapapa of health and engagement with health care. The stories are presented in two main sections: firstly, the interwoven whakapapa of land, language and health and secondly, whakapapa connections and disruptions. The initial section of this chapter focuses on the participants' stories of historical trauma as communicated through their whānau experiences over generations impacting their embodied experiences, choices and engagement with health care. Connections and disconnections to the lands that sustained their tīpuna/tūpuna demonstrate links between land and identity-making, economic potential, and consequently health and health care engagement. Where there were disruptions in access to land and cultural resources, and through urbanisation for all the women there was some disruption, there were rituals to support their identity as Māori in the urban area. For most of the women, however, there had been a disconnection with the language of their tīpuna/tūpuna, and a consequent disconnect with the passing down of knowledges.

In the second section the generational influences on the women's health and health care engagement present as persisting risk. I argue that the effect on the women of knowing, witnessing, caring for whānau with cancer or enduring illnesses, of untimely deaths in the whānau, is an enduring and inequitable burden of risk for self and other whānau. For those experiencing enduring illness themselves, the generational influences from experiencing whānau with the same illness influences their own embodied experience. The women's stories contribute knowledge of historical and ongoing processes affecting health and health care engagement informing Kawa Whakaruruhau/cultural safety theory for nurses (Ramsden, 2002).

Interwoven whakapapa: Land, language, health

The women identified their connection to the physical geography of their whakapapa land as an identifier of being Māori or iwi. Loss of land for whānau, hapū, iwi, is loss of wellbeing where the whakapapa of humans and the natural environment is conceptualised as a single entity. It is loss of an economic base. With replacement of land names by European names there is loss of Indigenous history held in the land-naming. Language loss is reflected in the loss of knowledges to pass on to the next generation, perhaps demonstrated in the many silences the women experienced in learning about their bodies.

Embodiment of historical trauma

Most of the women participating in this research told stories that illustrated influences from past generations, some of whom had passed away, on the health decisions they made for themselves and, at times, for their families. Women's views of themselves, their health expectations, embodied experiences and engagement with screening services may mirror the social and historical processes of colonisation. For example, one participant, Makere, remembers her Mother as working hard against a background of life-long struggle, accepting socioeconomic circumstances, hardship and illness as "women's lot" (Int.1) and the 'lot' of being Māori.

She was a battler. So she just used to carry on and work and get on with her life although some horrible stuff like that was happening to her ... I don't know how she coped, cause I never heard her complain. (Int. 1)

The impact on Makere of generational experiences is apparent as she recounted enduring nine months of suffering some years ago before she accessed health care:

My mum had a hysterectomy when she was in her thirties, cause she really suffered. I remember my mum used to heamorrhage all the time, and so I always thought that was going to be my lot, too, and my mum always said that to me, 'Oh well, usually this is what happens because of how I am, you're probably going to be like this.' So I don't know, maybe some of that was in my head, too, and I'm thinking, 'Oh gosh, must be starting' I suppose when you think about it there's a lot of generational thinking there that's passed down.... even now with terrible periods ... I kept thinking Mum would say, 'Well, it's not going to last forever. You just have to get through that time in your life' I just think she put up with a lot. I suppose that rubs off on me. (Makere, Int. 1)

From their time as Māori children at school and through their lives, Makere has a sense her parents struggled in their living and sees that as being an effect of colonisation. Her mother appeared to Makere to have the notion of her lot being part of her whānau inheritance, and as being a woman and Māori, and she put up with what was happening to her:

Makere: My mum came through a period where she was punished for saying the wrong thing ... yeah, her Reo and she always felt it was harder for them going to school. They always struggled a lot so I think a lot of that thinking has come from my mum... 'That's our lot.'

Interviewer: So she saw that as being the lot of Māori as well as the lot of women?

Makere: Yes, I think so. ‘You just have to put up with things cause that’s how it is’, is what my mum always said. And she did, too, my mum. She put up with a lot before she’d ever want something done or ever complain. (Makere, Int. 2)

Makere embodied her mother’s attitude grounded in historical trauma of losses and cultural alienations and on one level feels confused about what is normal for women. The generational thinking of ‘our lot’ that silenced attention to the body may also be reflected in H’s comment about the muteness of the older generation as they say little about their health or their bodies. She has noticed the beginning of a change from that view for herself in that she is starting to be aware of health messages that are ‘out there’:

You’ll find the old people still don’t talk much about their health... or about their bodies. So you know, it’s just for me in my noticing that ... I’ve really started to hear a lot about health out there. Before ... you just didn’t, you got sick and that was it. (H, Int. 2)

In contrast, another participant in the research identified a grandmother who had died two decades earlier as influencing a health screening decision. Anne attributed her resistance to free breast screening to her grandmother who, when as granddaughters in her care as small children, had demonstrated fretfulness about their bodies and in particular, concern to protect their breasts/chests from trauma, even before their breasts had developed. When Anne became eligible for free breast screening and began receiving information about mammography, her long deceased grandmother was against the procedure:

It took me two years to go and get a mammogram and that was because of my grandmother, and what she taught me since I was a child. My grandmother died when I was in my twenties, and when I was little we were never allowed to get knocks on our breasts, on our chest.... I didn’t have any but it was about doing that so I wouldn’t get sick later on.... So when it came to mammogram time and I started hearing ... all these horror stories about going to have your breasts squeezed and pressed... and my grandmother was totally against it. (Anne, Int. 1)

Anne didn’t know why her grandmother was against breast screening: “We don’t have a history in our family of having anything wrong with our breasts so I don’t know where it came from” (Int. 1). Her grandmother had cared for a number of whānau who had died from cancer.

She’d been to so many deaths, like she nursed all of her brothers and sisters and relations in

their cancer deaths. She would go to their homes and live with them until they died. She did that with [Grandfather]. She had him at home. (Anne, Int. 1)

While the development of cancer caused by trauma could possibly have influenced the grandmother's concern for her granddaughter's chests/breasts, it was fear of going against what grandmother said that influenced Anne:

The fear was about going against what my grandmother said.... She was quite influential in a whole lot of things in my life.... I lived with her.... She was just always in our life... much stronger than my mother's [influence, voice].... She was always very good to me. (Anne, Int. 1)

So Anne withstood breast-screening invitations.

Similarly, another participant attributed her mother, who had died in her early forties some years previously, with influencing delay. Dolores said her mother related well to Pākehā and had role-modeled and encouraged her large family to always dress well, her dress consciousness possibly contributing to Pākehā acceptance. So Dolores endeavoured to hide the seriousness of her distress in a recreational setting from her husband as she delayed seeking medical attention for several hours, returned home and with great effort showered and changed her clothes so, although ill, she could present at the medical centre well-dressed:

I've just got over having a slight heart attack... my husband and I went to get some pāuas.... I like the sea but I don't like going out into the deep and I felt I couldn't touch the ground, so I started to panic. And I just thought it was an anxiety attack... I got myself to the shore. It took a long time... feeling really, really terrible. When my husband realised what was happening, he said, 'Oh, do you want to go to... Hospital?' I said, 'No, no take me home.' Cause I wanted to go home and have a shower... the shower was hard for me. I tried to be strong. I didn't want to show my husband but he could just see the colour of my skin had changed. The clothes that I had on I wasn't really happy, cause I still wanted to look good while I go to the hospital.... My husband took me to the surgery.... They took one look at me and said you have to get on the oxygen.... The ambulance... came to get me and took me straight to the hospital Yes, that was the influence of my mum saying you always have to look good. (Dolores, Int. 1)

Anne describes a collective act of resistance by Māori to the embodiment of historical trauma. Māori were depopulated and the reproducing generations of the time made a commitment to

repopulate:

I mean for a whole couple of generations to go through childbirth at the rate that they did to replace the population was amazing. That was a real commitment to the health of the hapū, to replace the ones that'd died... My mother's generation, my father's generation when they had all those babies. It was a big commitment and it was done on purpose, cos women didn't have that many children. (Int. 2)

Traditionally Māori women, as seen in whakapapa lines, had few children. The dominant culture viewed the repopulation disparagingly, didn't understand the resistance:

In the whakapapa, women had two, three children, maybe, then they stopped, because they were a part of the community and the children was everyone's. But when the numbers dropped, and the leaders dropped, they made a concentrated effort... to bring children into this world. And it was across the country, that's why we had so many children. But from a different cultural perspective it was because they couldn't do anything else, and it wasn't. It was cos they all died off, all the children were dying. (Anne, Int. 2)

Anne connects this time to health policy development, legislation and budgets.

And I really don't like Mr Truby [King]³⁹... I don't like their whole health... policy development that he was part of. So I don't like the fact that there's such slow change to them. Like there's people learning about it but... they don't make the legislation, they don't make up the budgets... It's all very sad. (Anne, Int. 2)

There is a sense in these stories of other intertwining, intergenerational stories, stories without words even, but affecting current health and health care engagement of the Māori women participating in this study. There are resistances. Stories that are embodied in the fabric of the women's being may never be known or understood by nurses in a health care setting but are to be acknowledged respectfully as in Kawa Whakaruruhau/cultural safety theory. In the next section I will explore the effects on health and health care engagement of the generational influences associated with the loss of land with its various inherent meanings, through the processes of colonisation.

³⁹ Sir Frederic Truby King, (1858-1938) health reformer and founder of the well child organisation known as the Royal New Zealand Plunket Society (Brookes, 2012)

Land, identity and health

Most women in the study spoke of attachment to place, and notions of where they were at 'home', land of their whānau, hapū, iwi, tūpuna/tūpuna to which they whakapapa, the basis of their identity-making. Durie (1998) sees that access to place, to Te Ao Māori as a basis for identity formation, and for Māori as fundamental for the sense of wellbeing. Whakapapa land is to be cared for and about and passed on to future generations, as Dolores says: "So, you know...how important land is for us as a people, cos it's not ours, we're just the minders" (Int. 2). The women's parents, grandparents or tūpuna/tūpuna had migrated away from traditional areas to the city to find work but there were differences in the women's current ability to access traditional places and cultural resources. A few women had no current contact with their traditional land or Te Ao Māori.

Shar only knows the general geographical area of her marae, which she remembers visiting as a child. "All I know is it's up in the (region) somewhere" (Int. 1). Her Māori grandmother who raised her had lived in an era of enforced assimilation and disruption from cultural and economic resources (Hunn, 1961). Shar described her grandmother as, "quite uppity.... She never taught us [Te Reo]. She said it was a waste of time because it was not going to land you anywhere" (Int. 1). Shar's grandmother's disassociation from things Māori may have been an attempt to survive in a Pākehā world. Life has been stressful for Shar and resources appear limited. Shar has been to see the doctor about her chest pain, intermittent in sharpness and dullness, and in occurrence. There is a suggestion it is due to anxiety, which Shar doesn't believe, and she has had a chest x-ray with no result given her. The mental health nurse suggests an increase in her medication with her levels of irritability. There have been stresses with family health and it is an unknown how much lack of whakapapa knowledge and access to traditional place affects Shar's identity-making and current health:

I've had this chest pain for a very long time. They're saying it could be anxiety. It's not anxiety, I know, it's the same pain that I had with my accident ... it comes and goes, sometimes its dull, sometimes its sharp and I don't think he [doctor] can have listened to me.... The [mental health] nurse said I might need to up dose my medicine, depending because I breast feed [baby], because she thinks I'm still irritated, just a little bit, because of what's going on. Of course I'm irritated. (Shar, Int. 1)

Shar would like to visit her ancestral marae sometime, "When everything settles down" (Int. 1).

For Louise, the abuse and rejection from her birth mother has the effect she does not know her whakapapa from that side: "So therefore, she's not my mum. I've cut her off.... and basically she's not my children's Nan" (Int. 1). Louise has made some connections as an adult recently

with the father who lost access to her at her birth, and says she now knows the “basics” of his side (Int. 1): iwi, general geographical area. These disruptions in access to identity-making knowledge of whānau, hapū, iwi, to cultural and economic resources of her tūpuna, may contribute to her current self-assessment of her health and engagement with health care: “I am healthy but not in the mind, I’m not” (Int. 1). Action space, neighbourhood, (Goodchild, 2011) and traditional place are currently all disrupted for Louise impacting her health and health care engagement.

In contrast, H was born in a traditional rural area and migrated to her urban area where her parents found work and where she went to school and to work, and where she has raised her own children.

Home is my house where I have my children (*laughs*)... My little, little bit of land that I own in [suburb], that’s our home. But, I also relate to my home as being where ... my tribe comes from. So, you know I do talk about it, I’ll say, ‘Oh, home in [suburb] or take me home-home, so they know the difference... and I relate to Mum’s house is our home cos we were brought up there as children ... and then to go right back to [traditional tribal region] is... the final journey I guess you could call it cos I’ll never go back there to live. (H, Int. 2)

‘Home’ is the urban place of everyday routines for H, where she has lived and contributed to an urban community, and where she wishes to continue living and working. Her mother’s urban house where H was reared as a child is also ‘home’. “Home-home” is her traditional rural area birthplace, her whakapapa place where she goes for holidays and cultural events such as tangi and which is where she has told her family is to be her burial place with her tūpuna. H is proud of her Māori identity and is comfortable to acknowledge her father’s recognition of their other Settler heritages, too, that they are in reality ‘a mixture’ of ethnicities:

You know, I’m very proud of my Māori heritage and nothing will change that but ... like my Dad said, ‘...I guess every New Zealand Māori... has some sort of European blood in them because of the way that society is.’ So even though I class myself as a Māori I’ve got (European ancestry)... I’ve got a mixture ... that’s true, that’s life. (Int. 2)

Anne, who was born and raised in the urban area, is “...very comfortable here” (Int. 2) where she contributes to various communities. It is the place where her tūpuna lived several centuries ago. “We’ve been all over the place cause all the places are home.... We’re just a very many, travelled lot” (Int. 2). Anne’s chosen place of whakapapa identity is a rural area and that is “home” and she asks herself, “Why is that? Cos that’s where I choose it to be I s’pose” (Int. 2). She was named after her

grandmother, and her grandmother's mother; they were Māori midwives and delivered both Māori and Settler babies in that place and it's where she wants her ashes to be buried. "I want my children to go home, it's where I consider home.... Where I feel connected" (Int. 2).

Anne and H, as with some other participants, demonstrate a firm sense of identity based on on-going involvement and contribution to their rural and traditional place where one day they will be buried with their tūpuna, and their community contributions and connections with other Māori in the places in which they now live as home. Disruption affected others differently, for example, Ani whose dad was Māori and was not born in Aotearoa New Zealand:

... I definitely always had a close connection with where my dad's family was from... he was very proud of his whakapapa.... The idea was that we would always move back up to live. And I guess that's with me, too. You almost feel you're not at home, even though it's a place I've lived the majority of my life. I was born here (urban area).... This was a transitional space, a transitional place and I didn't feel I had a sense of rooting myself here. I still don't.... and I think that's from Dad. (Int. 2)

Ani identifies an urban space as the location of her birth and where she has lived most of her life. It doesn't have the emotional attachment of place for her, the connectedness of place; that's reserved for the traditional area of her father's forebears, like Indigenous Peoples globally (Cajete, 1999b). Both for her and for her father the traditional place has been an un-lived place of yearning attachment. It has not been able to act as an economic buffer in the hard times when Ani has not had her "life together" (Int. 1). "People went off after the depression, went to cities and... whatever reason it got to a stage of dilapidation before it was pulled down" (Ani, Int. 2). The marae has been recently rebuilt but Ani has not been able to contribute to the fund-raising. With urban migration came a break in family tikanga knowledge and trying to fit in with other tikanga may be "trying to be what you're not" (Int. 2).

Most of the stuff that I've come across, that wasn't passed down from my family... It might be Māori tikanga but it hasn't been passed down to me because of the gap when things stopped, things didn't get passed down. There's a gulf there, so I don't know what the tikanga of my tribe, my hapū, my family... trying to fit into tikanga that... that you haven't been brought up with and you don't even know where its come from, what the reasons behind it, can be a little bit...difficult, trying to be what you're not in some ways, you know. It's not in your heart, you're just doing it to placate someone and you don't know even who that person is. (Ani, Int. 2)

Each of the women's stories are in the context of Aotearoa New Zealand's colonial history of land loss and each story is unique in their access to land, and cultural and economic resources of their tūpuna/tūpuna affecting identity-making and economic potential, and potentially in turn, health and health care engagement. In understandings of difference in cultural safety theory assumptions cannot be made about access to tūpuna/tūpuna resources for identity making or as a cultural and economic base. There are stories, too, of connections to ways of being Māori in the urban area that the women told.

Rituals as resistances, identity and health

As urban and Māori the women told of birth and death rituals, of connections to their traditional place, and of place-making in their current action and community spaces. Aroha connects predominantly to her father's area. It is where they are taken for burial. "That's how it goes with us and that's a good thing, I think. It's what we know, that's all I know" (Aroha, Int. 1). Her mother's traditional links are disrupted. "I know where my mum's marae is but I don't know actually where" (Int. 1). Her mother's side are buried in urban council cemeteries, which Aroha feels "hasn't got a lot of meaning... its just that you're another number" (Int. 1). Travel with the tūpāpaku to place of burial in traditional urupā, for some a long day or night's journey, maintains connection to traditional place of identity. Others have tangi in the urban area, which lacks sense of place for Aroha.

Maria wants to be cremated and buried in the distant traditional area beside her mother and tūpuna, and where her father is likely to be buried: "You don't want to be somewhere where you hardly get a visit (*laughing*)" (Int. 1). However, when asked where 'home' was, she said, "I'd have to say it's here [urban area] (Int. 1)." She was born in the urban area and lives in the urban family "homestead" (Int. 1) where her parents have lived and where the children's whenua have all been buried. Burying pito and whenua may be an act of place-making (Gesler & Kearns, 2002), and Aroha's mother has similarly been returning the whenua and pito to Papatūānuku, Earth Mother, in their urban place. It is a traditional ritual that contributes to place-making where the grandparents have raised their children, welcomed their grandchildren and around which they have contributed to their community in their urban space.

H first gave birth as a young teen. Her grandfather held her hand, while her parents were at work. It was her only afterbirth buried.

When I had my first child we did bury... the afterbirth, but the others I didn't.... I don't not believe that it should be buried... because I believe in the old days, that's what they did with

the after birth. They'd either plant it or they'd put it in a special place, yeah. But I just every time I had my babies, I forgot. (H Int. 1)

H's daughter was not aware of the tradition growing up and when hospital staff put her baby's after-birth in a plastic container H explained the significance to her and it was buried in the urban area:

She was quite happy to take it home and plant it under a tree... She said, 'I think that's neat, Mum, it's special. I'm taking [name's] afterbirth. I'm taking it home,' and we had a little karakia and she buried it. (H. Int. 1)

Anne doesn't know where her own whenua went in the "disassociation and dislocation" (Int. 2) from tikanga Māori: "Mother never got them, didn't know to get them" (Int. 2). In those days whenua went to the hospital incinerator, or down the sluice, or to benefit powerful others. In my experience as a student nurse in delivery suite about that time, some placenta went to the night charge midwife's rose garden, most likely without whānau knowledge. Anne's own first hospital births "...had been clinical" (Int. 2) and there was no one to look after her babies' whenua for her. "Just didn't think about it. I was too much on that other track, on the urban track" (Int. 1). When hapū again and at a hui, fellow attendee, Irihapeti Ramsden,⁴⁰ had encouraged her, "Now you remember when you have [baby] that your tīpuna are right there.... If you are having problems, they're right there" (Int. 1). With the whakapapa and spiritual connection to tīpuna, Anne felt she had more control: "Oh, this time I'd be in charge. I didn't do the things that they [hospital staff] said ...would be convenient for them. I did what was good for me" (Int. 1), and that included having supporters at the births and keeping the whenua. In addition Anne says, "Oh, I went the normal track, like go to the ante-natal classes, do all the things that you're supposed to do" (Int. 1).

Anne wasn't with her daughter at the birthing of her mokopuna but she is planning to take mokopuna's whenua back to the traditional area she calls home: "Because it was so quick [daughter] had just totally forgotten about it [whenua], but the staff put it aside and then later on they said to her, 'Here it is' I'm about to take it home" (Int. 2). Taking the whenua back to the traditional area connects mokopuna to that place and Anne thinks hospital staff should universally return whenua. "Well the fact that their whenua is in the ground makes them tangata whenua actually. Cos that's a connection that they have" (Int. 2).

⁴⁰Māori woman, activist, leader, Kawa Whakaruruhau/Cultural Safety theorist, Registered Nurse, Doctor of Philosophy.

When Ani's children were born she froze the placentas until she was able to take them back for burial at the foot of a totara tree in her traditional land, guided by her dad's cousin, the designated kaitiaki, and with karakia. Ani hopes the connection and tradition will continue for her children's children. For example, natural birth:

Indigenous People ... pre-industrial ... Māori, having a natural birth ... the 'hā,' the breathing, the whole being in touch, like the connectedness ... natural rhythms of your body.... that's the way it would have been for Māori, its natural world and I guess it could be pertaining to any culture ... in touch with the natural world.... I loved the whole birthing process. It was very spiritual. (Ani, Int. 1)

A contemporary reality for Māori and identity formation is that of mixed heritage. Angel's school-age child understands she is Māori because they return to their rural marae for family events such as tangi; it is more difficult for her to accept that she has [another ethnicity] heritage as they have not been able to afford to return to her father's traditional place in another country.

With my big girl she's, 'Mum, I'm not (another ethnicity), I'm Māori'. And I'm trying to explain to her, 'No, no, cause your dad's (another ethnicity). You're part of that culture, too'. But she doesn't accept that...yet. She accepts that she's Māori, because we always go to functions back home. (Angel, Int. 1)

A secure identity is a fundamental of good health (Durie, 1998) and the participants have varying experiences with possible effects on identity formation (Durie, 1997b). Resistances to assimilation may be seen in rituals. In the next section are examples of disruption of whakapapa knowledge.

Language and health

The historical devaluing and ongoing loss of Te Reo has been systemic and effects tikanga, dialect and iwi identity, transmission of historical knowledge, for example, of science, the environment, and ways of living. Anne relates:

I believe Māori women were so much healthier than they are now and the Reo has a lot to do with that cos in the Reo, is how you relate to people and not having our language has been to our detriment. Not having the position of te whare tangata acknowledged by the culture that's running our health service... our country.... They don't see any worth in our culture, and our culture sees worth in us and in keeping us healthy. That's all I have to say about it. It's very annoying, very, very, very, annoying, very anger making; the statistics, far too many... bad statistics. (Int. 2)

While the women all prized Te Reo, most did not have, or some at a particular time did not value, the opportunity to learn Te Reo. Te Reo links Anne not only to being Māori, but through dialect to her iwi roots, which is now written and goes back to her waka: “Dad can remember hearing s’s from his old line... I only heard the l’s and the k and I used to hear that from Aunt [name]. She was a beautiful speaker; had a wonderful karanga” (Int. 2).

The effect on wellbeing of the debasing of Te Reo was expressed by participants, for example, Makere earlier in the chapter, contributing to a sense of struggle in their living. Her dad only wanted them speaking English so they would have a good education and her mother could only pass on Māori knowledges when her dad was not there, as Makere explains:

My dad always believed that no good would come of us if we start delving into Māori things. We needed to be brought up speaking good English and getting a good education, because seeing what had happened to his older brothers and sisters at school. If Mum ever told me anything it would be when my dad wasn’t there. The only time I can remember my mum doing karakia was in times when I was really sick and the other time was when I got rheumatic fever and I remember my mum praying at the end of the bed.... When I went into hospital my mum come in, she didn’t say anything but she’d just sit there. (Int. 1)

There is a sense of Makere’s mother being unable to do for her family what she knew to do as a Māori woman, and of her father wanting to protect his family from the treatment he had witnessed metered out on other family members for speaking Māori at school.

Mary recounted the effect on her father of physical punishment being ‘caught’ speaking Māori at school:

Dad used to get the strap for speaking Māori at school and he always said to his father, ‘I’ll never let my kids go through this. I’ll let them decide what they want to learn’.... Mum had it easier cause the teacher was Māori and they all spoke Māori... they called it a Native School. (Mary, Int. 2)

Despite her mother’s positive experience at a Native School the overall effect of language devaluation in Aotearoa New Zealand was that most of Mary’s siblings did not learn Te Reo: “The only one that could speak it fluently was my younger brother ... he learnt it in jail” (Mary, Int. 2).

Learning Te Reo in jail is no substitute for learning Te Reo at home, in the neighbourhood, at school, equally valued with the now dominant global language. Dolores was from a large family and her father was fluent in Te Reo. He was brought up by the old people, and never went to a formal school. While Te Reo's relevance was not apparent to her previously, Dolores is now learning and her firm identity construction is Māori.

So when he come to the city he self taught himself. My dad loved reading, aye.... He asked me, 'Would you like to speak Māori?' and my answer to him was, 'What for?' But that didn't stop him from speaking Te Reo... from being involved in things Māori.... So I mightn't be a fluent speaker but my heart is there as a Māori. No one can take that away from me. (Int. 1)

H's father was also a fluent Te Reo speaker and knowledgeable in tikanga, but he didn't want to pass on his knowledge to his children:

Because of his beliefs and what he's experienced as a child through Māoridom, he didn't want that to rub off on us. So he didn't even teach us to speak Te Reo Māori. Cause he didn't want what he knows to be passed down to us. He wanted it to finish at his level. But it didn't, it passed on to me. (H. Int. 1)

Tairua spent significant time in her childhood with her grandparents in a rural area where more Māori lived. She learnt Te Reo "... from my grandparents ... I was more with them than I was with my mum.... I'm quite fluent, so I hope (baby) ends up being like that as well" (Int. 1). It was different for Shar, with her Māori grandmother disassociating from place and Te Reo as mentioned above. Shar is concerned for her children's identity construction: "I talk a little bit, only the basics because I learnt that at school. (The children) know some basics but they need to know who they are... (Shar, Int. 1).

Devaluing Indigenous language excludes a unique worldview and normal linguistic development (Chumbow, 2005). Language devaluing affected what and how women learnt about their bodies and maintained their health.

Preparing growing bodies: "I was never learnt any of that"

The first remembered significant gendered health event for most women was menstruation. Menstruation visibly heralded womanhood; it required certain specific knowledges, practices and rituals. Most of the women learnt about periods after they had started menstruating, most were welcomed into womanhood and given hygiene information. There was little about

growing bodies, having babies or avoiding pregnancy. Sometimes other family members or friends shared their understandings, a few learnt at school. Some learnt about Māori protocol for times when menstruating or hapū in the global language from parents or other family members. Most expressed a sense of unpreparedness, as H explains:

My mum didn't talk about things like that. So I had to teach myself plus my sisters.... You know sexual health wasn't around in those days, so you had to learn the hard way, I guess. And I guess I learnt the hard way 'cause I had a baby at sixteen. (H. Int. 1)

Mary thought she was dying. Her mother then gave her the functional, everyday understandings of managing the process of menstruation:

I went to the toilet... I came running out saying to my mum, 'I'm dying, I'm dying...blood is coming out between my legs.'... 'No, you're not dying,' she said, 'it's your period ... It's what you get, when you get to a certain age, and you sort of develop.' She showed me what I had to do... and she told me, you'd be getting it monthly. And she said to write the day down on the calendar, to keep a record.... 'It was part of you becoming a women.' But I said, 'Well, I'm not a woman, I'm only ten years old.' (Mary, Int. 1)

She showed me the strap things and you pin it on to the pad. And she said, ... 'Black knickers are better to wear.... You can still play sports.... You don't have to play...when you've got your period'. And I asked her how long it took. She said, 'Sometimes five to seven days.'... 'Oh, heck, ... that's going to ruin my life.' She said to me, 'Girl, you've gotta get used to it because you going to have it for the next thirty or forty years'. (Mary, Int. 1)

And she told me to have showers everyday when you've got it, you've got to wash your knickers and everything... make sure that when you change...[pads]...that you wrap it up neat, and put it in the rubbish bin.... She just called it 'period'... She could speak Māori fluently, but she just you know, explained it to me in English. (Mary, Int. 1)

Mary's dad welcomed her womanly status, and her mother gave to her the Māori understandings of generations of Māori women in their whānau for times when women were menstruating or hapū:

She told Dad, and Dad...says to me, 'Oh, you're a woman now, Girl' We had to keep out of that river ... you know the blood.... We were told by our mother, and my mother was told by hers, that if you were pregnant or you had your period...you were never allowed on to a grave ... you weren't allowed around the body.... I think every mother tells their daughter about the hygiene of having periods, like you have to keep yourself [clean]... but my mother taught me about Māori protocol. (Mary, Int. 1)

Patricia, too, describes her pre-teen alarm. Reared by her father and stepmother, she wasn't prepared for reproductive health: "No, I was never learnt any of that" (Int.1). In her whānau, twenty-first birthdays were a big celebration, but only if the twenty-one year old had not had a baby, and Patricia had several children by twenty-one.

Well, I freaked out when I got my period because I didn't know what it was. I went 'Dad, I'm bleeding out of my bum' I was like, ...10, 11. But then no-one told me –[about] period[s] or that I was going to get boobiesIf I had known a lot I wouldn't have had a baby that young. I'd probably wait until I was like twenty, or over twenty-one.... I was working my way to wanting my twenty-first, but that didn't happen. (Patricia, Int. 1)

As a first-time pregnant teen, Patricia was initially seen by her general practitioner and twice by midwives. Her family informed her about childbirth:

Well, while you're giving birth wasn't very nice. They said that, but once the baby comes out you'll be happy, mm better and you'd feel happy...they didn't talk to me about feelings, nah.... I was very unprepared. I was prepared for the baby stuff. Got a lot of ... I was very unprepared for myself, for my health. My own self, I wasn't prepared for that. (Patricia, Int. 1)

Anne learnt about periods at school and when she was hapū her grandmother asked, "...what was I doing about cutting my nails [and] how are your teeth?" (Int. 1). Her grandmother instructed: "Don't reach above your head... Do not cut your hair while you're pregnant." Anne feels she learnt about babies from helping with younger siblings: "I pretty much knew what to do with babies" (Int. 1). An uncle on Makere's mother's side asked Makere if she had her period and if her mother had told her anything about the Māori side, and as her mother hadn't, he undertook that responsibility. In their whānau women who were menstruating or hapū were not excluded from a dying person's presence or the urupā, rather they were to keep away from food sources, places of calving when hapū. He came and performed karakia ceremonies when her first baby was born and was disappointed the baby's

whenua had already been disposed of.

My uncle...Mum's brother...told me not to ever go out and get kai moana, that sort of stuff. He told me about blood...that for Māori that's a sacred time, yeah...and you know like...to be mindful when you dispose of your pads and things like that. And I felt comfortable talking to my uncle; he was a lovely uncle. (Makere, Int. 1)

Shar's grandmother was silent about bodies and periods and when Shar began menstruating in her early teens, Shar turned to her elder sister for support: "I think I told my sister because I didn't know what" (Shar, Int. 1). Tairua similarly experienced whānau silence. When menstruation began her mother announced her womanhood and gave management information: "Oh it wasn't much ... it was just that when I did first get my period she said, 'Well you're a woman now, you gotta start wearing tampons', or whatever, yeah that's pretty much what she said" (Tairua, Int. 1).

There were wisdoms from previous generations of women about bodies such as Dolores interpreted from her mother and grandmothers, one of whom was a Māori midwife and kaikaranga:

Coming from those two women (grandmothers) and my mum was to appreciate my body and to treat it as such with respect; it's holy. We are also the ones that bring life into this world, so we are treated as such, you know. So I'm lucky that I was able to bear children. (Dolores, Int. 2)

Similarly, H relayed what her mother says to all her grandchildren: "...my mum has a famous saying, 'Women sit on a goldmine because we bear children' " (H, Int. 2).

Overall the women experienced silences in their preparation for sexual and reproductive development. In Kawa Whakaruruhau/cultural safety theory the difference between the nurse and the recipient of nursing care may mean appreciating events impacting a woman's preparedness for managing her sexual and reproductive health. Respecting differences may mean respectfully understanding information silences about bodies or Māori protocol from a generation past to the generation current. It may mean acknowledging and respecting the sacredness of the women's knowledges of Māori protocol for women and their bodies that may differ whānau to whānau.

The interwoven whakapapa of land, language and health reveals aspects of the landscape of

urban Māori women to inform understandings of difference in culturally safe nursing practice. Generational influences affect the women's current health decision-making. In the second part of this whakapapa of health the women tell stories about illness, their own and caring about and for whānau, with the effect of embodying risk.

Whakapapa connections and disruptions: Effects of enduring risk and illness

Most women in the study related their experiences of knowing of, and caring for family with illnesses, which included notions of heredity, inevitability, not wanting to know, fear, risk, curse, 'being checked', and lifestyle. The fear of 'that word', cancer, or other enduring illness, is accompanied by the fear of pain, disability, concern for the care of dependent whānau if ill or dying, having an intervention and still dying. The responses of the women were individual and varied influencing health and health care engagement. Their experiences reflected population inequalities both in contracting the illness and in access to treatment.

"I get worried I might get... something"

In the first story a young woman with small children experienced the deaths of both parents in their mid-lives and is worried about her own health. Fran returned with her young children from caring for her mother who died from cancer, to a new baby and her father's final hospitalisation with emphysema; her mother was in her late forties, her father his early fifties. They were difficult days and the fear persists: "I'm just worried about my health from seeing them die so young. I get worried I might get cancer, might get emphysema or something" (Fran, Int. 2). Fran lives with the fear of the unknown, a sense of risk of illness, and seeks help from health services. Her experiences of seeking help are for the next chapters. She has experienced the resources of the family being overwhelmed, but also knows support from family and friends. Two other participants, who were interviewed together, told of intergenerational sudden death. The generational influences from the unexpected passing of whānau hovered as risk over the landscape, hurting solutions by whānau darkening the view:

Apparently, we've got a suicide curse on our family handed from my father's side, everybody generation to generation to generation (Angel, Int. 1)

.... I never knew her [mother]... Twenty-seven when she died. But the funny thing was her mum, my mum's mum died at the age of twenty-seven, too (Patricia, Int. 1)

.... first thing you see is alcohol, and grab one. That will stop that hurting process for a little bit ... (Angel, Int. 1)

.... But in the morning its back (Patricia, Int. 1)

It's not going to deal with the issue at hand. (Angel, Int. 1)

Pain is persistent in the ongoing sense of loss and grief and risk for Patricia and Angel in their different circumstances. Angel concludes alcohol abuse does not solve problems.

In Aroha's story, acute bodily dysfunction was experienced against the background of whānau illness, risk, and fear of knowing. One fear concerned care for her children, another about the suffering she had witnessed. Aroha locates the pain similarly to where she understood whānau members with cancer had suffered:

I only asked him... [doctor]... because I was there for something else... otherwise I never would probably have gone there unless I was in excruciating pain. But they were kind of scary pains and I didn't want to know about them.... because I'd get scared it could be something really bad and I don't want to know if something's wrong. I know you can get help but I always think that inner, internally, and all this area... [indicating pelvis, abdomen, chest/breast]... torso I suppose. And then we've had cancer in the family, you know, take members... I just get scared of who's going to look after...[her children]... It's been a bit of a rough road being on our own.... Pain would be probably excruciating, totally out of my head. (Aroha, Int. 1)

Some women believed their families had a lot of cancer, or cancer in the genes, as Marie who cared for her mother in her last two years says:

My mother passed on with breast cancer apparently. She had the most aggressive breast cancer and she also had secondary cancer in the bone.... I've had a cousin pass away recently; she was 53 years old... cancer. It's rampant in our family for some reason.... in the genes.... Ah, I had two other cousins die really young... of cancer, breast cancer. My aunty passed shortly after those two girls. And another aunty has cancer and another one that died Christmas... breast cancer and lung. My nanny died of lung cancer.... [She]... never, never smoked (Int.1).... That word [cancer] to all of us means, 'I'm going to die soon'.... after that you're not going to hear all the other stuff [treatment options and follow up]. (Int. 2)

The word 'cancer' portrays risk and intense suffering and end of life and affects treatment decision-making.

Makere had known a number of whānau with cancer so that when she was aware something was wrong with her body Makere delayed attending a health service. Contributing to Makere's delay was not wanting to know and lack of information about cancer, treatment effects and effectiveness. Her general practitioner (GP) provided helpful information as Makere explains:

I think I sort of didn't really want to know ... I thought something was really wrong and then the thing about cancer in our family, everybody died.... 'cause they all went too late.... to hear that word was like a terrible word in our family. So, yeah some of it was myself knowing something's not right here but... not really wanting to go and find out what was wrong. You don't have the same access to information.... Cancer...[treatment]... can have a good outcome. I know that now but I certainly didn't know that then. And then I thought, 'Oh my gosh, what say they take all my insides out' (Int.1).... It's easy now you can go on the Internet but I didn't know where to go to get more information.... It wasn't till I went back to my GP really that he told me. I think I'd sort of decided, ' I'm not going to bother going then, if that's the case, what's the use? Look at my aunty, she had her breasts removed and she still died' But, yeah, he was good. He talked about it. (Int. 2)

H told the stories of her interactions with two women and their understandings of screening⁴¹ and illness and the first story, similar to previous participants', demonstrates the effect of generational influences, as H related:

My cousin passed away from cervical cancer and her mother did.... I used to be with her sometimes and she was always going in and out of the toilet. And I said to her... 'Have you had a smear, Cousin?' She said, 'Cousin, I don't like smears' and I said, 'What's up? You shouldn't be always going to the toilet like that, Cousin'. And she'd go, 'Oh no, I've always been like this'. Then she got diagnosed with cervical cancer.... She was scared of the unknown. Māori women get scared to have smears because [if]... they've got cervical cancer, they'd rather not know. (Int. 1)

Similarly, in the second interaction H related that when another woman returned after attending breast-screening H asked her: 'How was it?' And she goes, 'I shouldn't have gone.... cos they found something' (H, Int. 2).

Knowledge of cancer in the family at times encouraged intergenerational support. Dolores describes talking to her aunt for whom presenting an intimate and private body area for cervical screening, maybe for the only time, was distressing:

⁴¹ The women in the study had all by the time of interview been invited to attend or had attended well women screening. In Aotearoa New Zealand the ages for cervical screening are 20 to 70 years of age, for breast screening 45 to 69 (National Screening Unit, 2014c).

She hadn't had a smear test... so I had to talk to my aunty. 'Oh, nobody has been there but my husband.'.... 'I can come there and support you if you want to.' So I did and it was quite an emotional time for my aunty. Even though they had explained, she cried as it was getting done. (Dolores, Int. 1)

Makere saw the extent and the effect of illness in her mother's family, one line of which had been identified as having a gene for a particular cancer. Her mother had lived the longest of her siblings, who had died early, as she relates:

They all died. My mum was the last one in her family.... Just about all her brothers and sisters died of cancer, or heart or diabetes. Mum's family has a lot of diabetes in it. Yeah, so... Mum didn't have diabetes though, the rest, a lot of her brothers and sisters had it.... a few of my cousins have got diabetes. They'll be in their thirties, forties. (Makere, Int. 1)

The experience of having whānau suffer with illness is difficult and it influences women both to attend and to not attend health screening and health checks, which supports other research (Kahui Tautoko Consulting Ltd, 2007). Some participants describe the experience of being involved with whānau with enduring illness and then being diagnosed with the same illness.

Embodiment of illness: "My diabetes"

Experiencing disruptions in family life through illness seen as in the genes, and the use of resources to care for suffering within the whānau impacted health decision-making. Mary describes resisting medical investigations for several years through fear, even though she considered her father managed diabetes well. At that stage of her life Mary had rarely been to a doctor. There could be a sense of resisting an ongoing condition perceived generally with disapproval, the sufferer viewed as responsible for their own illness (Estroff, 1981, 1993). Rather than being an individual condition, Mary relates how her family encouraged each other to go for testing, "Dad made me go and check my diabetes. I was the last, my other brothers went; I think it was the fear" (Mary, Int. 1). 'My diabetes' is possessive; Mary identifies as owning, inhabiting the enduring condition (Estroff, 1981, 1993).

As Mary restabilises her own identity she assigns a different identity to the one brother who didn't develop diabetes that reflects his dissimilar lifestyle from that of the rest of the whānau who did. Although Mary had been physically active earlier in life, this brother had maintained physical activity, as she explains: "...he still does his running now.... ...he wasn't a lolly type; he wasn't a chocolate type or anything like that. He wasn't into the chippie or the coke type or

the pie type. Never ate those sorts of things” (Mary Int. 1). Mary credited her brother’s lifestyle with disrupting the whakapapa of enduring illness in their whānau, but another participant, Dolores, appears to view enduring illness in the whānau with inevitability. Both view diabetes as an inhabiting identity. Dolores’ mother died in early mid-life, and Dolores cared for her father who had diabetes and died of diabetes complications. When Dolores had a heart attack she was diagnosed with diabetes in the ensuing investigations:

But even then I didn’t...believe it was a heart attack. But they said it was, and then from there it brought on my diabetes, because diabetes runs in my family so it is hereditary. We also did a whakapapa on both sides of my parents but predominantly on my dad’s side because all his siblings, plus his mother, all died of diabetes.... so my dad died of diabetes and ... I just know anyway that... it’s going to happen to me sooner than later cause most of my siblings are also diabetetic. And I got it at a late age...fifty-two.... I’ve seen what diabetes can do 'cause I looked after my dad.... The thing is with diabetes you can’t see it, so it’s a very slow death. That’s how I see it to be. (Dolores, Int. 1)

Dolores’ parents were part of the post-war rural-urban migration and assimilation, which impacted the wellbeing of Māori as suggested in earlier research (Price, 1939; Prior, 1971). Looking at outcomes for whānau during that period Dolores understands the enduring illness from which she suffers as embodied and inevitable, an understanding that may reflect inequitable structural factors such as regular and affordable access to appropriate primary health care, knowledge and support (Tobias & Yeh, 2007). Inequitable structural factors may be interpreted as ongoing processes of colonisation.

Conclusion

A whakapapa of health demonstrates the generational influences in the landscapes of the women’s experience of health and health care engagement and contributes to whiteness theory and to the categories of difference and power in Kawa Whakaruruhau/cultural safety theory. The embodiment of historical trauma and assimilation in previous generations, who did what needed to be done for survival as Māori in a colonised world, has on-going intergenerational affects on health and health care engagement. The devaluing of Māori knowledges, epistemology, and Mātauranga Māori affected customary cultural transmission and routine ongoing language development. Gender-related effects include preparation for menstruation, pregnancy and childbirth, for knowing what is ‘normal’ in on-going health maintenance and health care engagement. There were at times life-enhancing resistances, such as repopulation and ritualising connections with being Māori in the burying of whenua and pito in an urban

place of meaning, and the giving of cultural knowledge concerning menstruation, pregnancy and childbirth by parents or other whānau.

The women have experienced illness, both those of whānau and their own, as a whakapapa of enduring risk. An illness that is in the family, in the genes, has implications both in the inhabiting of the disease, and in the fear across the generations of diagnosis and vulnerability. Inequity in incidence of illness and access to treatment is experienced as limiting and persistent risk. Suffering an ongoing condition, or knowing about or caring for whānau suffering produces vulnerability and fear of diagnosis or complications of the experienced illness. Vulnerability and fear inequitably experienced impacts health and both encourages and discourages women's engagement with health services. The next chapter will examine the geographical concepts of space and place, networks and (dis)connections that are part of the women's health care engagement, elements in their whakapapa of health.

Chapter Six: Contested landscapes: Space, place, networks and connections

Landscapes, to the purposeful viewer, comprise spaces and places, connections and networks, that in a whakapapa of health contribute, or not, to wellbeing and health care engagement. The history of space and place in Aotearoa New Zealand has been described as physically and metaphorically contested (Mikaere, 2011). White landscapes are based on powerfully excluding from the benefits of society those who are different (Mikaere, 2011; Sibley, 1995; Tyler, 2012). The contest of power in the whakapapa of health landscape may be observed in the first of two main themes in this chapter as power relations and spatiality, and in the second main theme as the body as geography and body in geography. In the first theme there are stories of both professional-centric and whānau centred services which, when seen against the context of the women's socioeconomic constraints, differently engage with power. Publicly funded services purportedly provided for the benefit of all, through issues of power may systemically exclude those who differ from the white norm. In this study, young and Māori could be seen as systemically excluded from, for example, antenatal education, through not being able to access a service where their needs were central. The meaning of time in the women's stories has a relationship with the meaning of place. Time taken by health professionals in the provision of health care affects the meaning of the health care space and is related to the achievement of wellbeing.

In the second theme the stories demonstrate how the contested nature of the gendered body in health care spaces affects health and health care engagement. The quality of a relational, respectful and perceptive approach, concern for the whole person not just the physical procedure, the giving of information appropriately, enables women to rationalise sensitive conversations and intimate procedures. Abusive spaces encountered in a woman's life from pre-birth, or in her growing years to present adulthood, are experienced as a disempowering and potentially life-threatening landscape, the memory and effects of which remain. Health is experienced to the extent contested landscapes of space and place, networks and connections to and between spaces and places enable or disable culturally safe health care provision, promote or suppress an authentic whakapapa of health.

Power relations and spatiality

In a whakapapa of health, power associated with places and spaces in a landscape is not inherently neutral. Interrogating power in health care relationships is at the base of cultural safety theory in the nurse/whānau relationship (Ramsden, 2002), and in health provider systems (F. Richardson, 2010). In this section there are three interrelated themes that interrogate that

power: issues of power and poverty, systemic exclusions, and the relationship between time and spatiality.

Issues of power and poverty

The women told of powerlessness, being isolated in health service encounters by ethnicity, gender, socioeconomic circumstances, choice of health provider and place to live; stories reflecting health professional behaviour and structures of power in serving a population for their health needs. There were alternate stories of engagement, understanding, information and support, appropriate treatment, health-enabling agency, and stories of the women's resistances.

For Makere, issues of power are related to colonisation, reflecting the previous chapter, affecting both types of illnesses and services Māori women received:

For Māori, a whole lot of their experiences are a direct result of colonisation. The types of illnesses that Māori women were getting, ...just the whole coldness of the service, that's not something I think, that Māori are used to. Back then anyway, the way that you were provided with services was not conducive to Māori being well, healthy, really. And I think a lot of that is just the whole colonised processes of dealing with things and I think then we had silos. The hospital didn't talk to the GP really well and because I remember waiting a really long time before my GP got my results but there was that process they had in place and you couldn't alter it in any way. I had to wait until my GP got my results before I could go and talk to my GP. (Int. 2)

Makere uses one of her stories as an example of health service disparities in the giving of information. A health provider contacted by telephone a Māori organisation with whom Makere was not affiliated. The health provider wrongly and inappropriately gave Makere's information to the first person that answered the telephone. Health provider power relations were erroneously extended into an employment network space. Makere compares this to how a Pākehā woman from a comparatively affluent Wellington suburb working in a Central Wellington government department would receive personal information.

It made me feel really sick that they had rung somewhere completely different and even that whole process of ringing someone and telling them at work (Int. 1)... and giving results to whoever answered thinking we're all family on the marae.... (Int. 2) [This equates to] ... a Pākehā woman living in somewhere like Karori or Khandallah⁴² [working] somewhere

⁴² Karori and Khandallah are least deprived areas in the nearby city of Wellington and are in stark contrast to the deprivation status of the area in which Makere lives as substantiated by the

like Inland Revenue and the [health service] telling the first person that answered the [Inland Revenue] phone. (Makere, Int. 2)

Now having been given more information about her health and what to expect from health services, and having had some positive and empowering experiences Makere concludes: “I’m a much different person now.” (Int. 2)

In primary health, issues of disempowerment and poverty may be reflected in the women’s feelings towards a local systemic shortage of general practitioners⁴³ and an over-reliance on locum doctors is in the naming: “randoms,” (Shar, Int. 1), “fill-ins” (Fran, Int. 2), and the women lacked choice of health care provider:

He was not the doctor I was supposed to see. I wanted to see the same doctor that had seen me the first time ... not another random.... I don’t like locum doctors at all.... They only read what’s on your screen. (Shar, Int. 1)

First time I’ve seen him, I think he’s a fill-in, you know how they have extras. (Fran, Int. 2)

Not having the same doctor or nurse was seen to hinder relationship building and a sense of family history being understood, which sometimes was felt to affect the level of care received. Shar, her baby and preschooler all had ongoing health issues and they lived in social housing in need of an upgrade. It was difficult at times for her with financial limitations to attend to her own and family care. When at the medical centre for herself, Shar felt rushed and her needs ignored by the scheduled locum doctor resulting in an unsafe consequence:

I tried to tell him about it and he completely ignored me: ‘One thing at a time.’ ‘Excuse me; I’m paying fifteen dollars, what for? A two minute consultation?’ You know. And he was not the doctor I was supposed to see. I wanted to see the same doctor that had seen me the first time.... There were lots of things I needed to tell him that day but I was rushed, and I told him about my asthma. He didn’t even write me a script.... The other day I had an asthma attack. I had to use my daughter’s inhalers. If she didn’t have no [inhaler] I’d probably end up in hospital. I was choking

Atlas of Socioeconomic Deprivation in New Zealand. NZ Dep 2006 (White, Gunston, Salmond, Atkinson, & Crampton, 2008).

⁴³ Hutt Valley District Health Board (DHB) in 2011 had 61 full time equivalent (FTE) general practitioners (GPs) per 100,000 population compared to 75 FTE per 100,000 for NZ as a country, placing Hutt Valley in the lowest ranking quintile of GPs per 100,000 (Medical Council of New Zealand, 2011). In 2001, Hutt Valley DHB had 74 FTE GP’s per 100,000, compared to 83 FTE GPs per 100,000 for NZ as a country (Medical Council of New Zealand, 2001).

cos I had a sore throat and I was coughing and I was gasping for air. If that doctor had given me a prescription I'd have been fine. Now my daughter has to go without because I had to use hers.... I was pissed off.... I don't like being passed doctor to doctor. I like to have my own doctor not heaps of doctors. (Int. 1)

Shar knew she needed good self-care to enable her to care for her children and she wanted a doctor who knew her history and would make connections for her, someone to whom she could relate. Anxious and frustrated with the powerlessness, Shar says: "And its like you need to take care of yourself to take care of your babies and I know I don't" (Int. 1).

In the same consultation Shar requested a repeat prescription for her baby's conjunctivitis. The locum doctor told her to go to the pharmacy that had dispensed the previous prescription, find out what had been dispensed and then he would prescribe. That pharmacy was a ten-minute car journey away, there was no direct public transport, Shar and her small children struggled with their health issues, and it is difficult to imagine that the information was not available to him:

Then I asked, this one had conjunctivitis, and I told him what it was, what kind of eye drop it was, it was chlora ... something. And him being a doctor he would have gathered what I was trying to say. He said, 'Go to (named) Chemist, ask them what it was called and then I can write a prescription'. He should have known from the files from another doctor. (Shar, Int. 1)

Shar relates an experience where a power differential was played out between the gendered, socioeconomic and possibly racialised space she occupied, a space with little choice, and the medical consultation she attended. She, a woman and mother, vulnerable with competing needs and responsibilities, seeking his medical services; he, the holder of resource and privilege limiting her access right for his own reasons. One possibility is his frustration at a request for a child's prescription when the consultation was for the mother. Women burdened by systemic, multifactorial issues of poverty, have a right to health provider management systems that promote health professional/whānau/community relationship building, a right to be connected to networks to address socioeconomic determinants of health.

Economic poverty relates to environmental stress through poverty, and most women had the major responsibility for their families, with little choice over housing and difficulties in accessing appropriate health care support. Fran describes a disconnection between her relationship to her home and her relationship to health care that affect both her health and that of her family. They live in a damp, private rental house in a low socioeconomic area needing transport to amenities, and Fran and

her children suffer from asthma. She contrasts the medication focus of the medical centre she attends with the help she received with asthma education and support, healthy housing interventions, and becoming part of asthma research through Tu Kotahi Māori Asthma Trust:

I used to go there [medical centre] and say, 'Look, I'm not feeling very well.' They don't put me on to no help. It was just, 'Here's your pump,' and that's it.... straight out medication. I didn't get the help until I jumped on with the Māori Asthma Trust.... Not even for my children when they're asthmatics.... I've been asthmatic for years (Fran, Int. 1).... I've been safer with that [Tu Kotahi Māori Asthma Trust] because of the support with my asthma. And being on the asthma study that was excellent. That really helped me... because it got me on to the right medication that I needed, also all the support and information from the researcher and the nurse that used to come with him. It was just a lot of support and a lot of information that really helped me, yeah. And now I get to use these pumps that help me more than my old pumps. So now when I go back to the doctors it will be on file from them for me to have those new pumps from now on, yeah. So that's cool, my meds have changed and I don't feel so breathless, not so breathless. (Fran, Int. 2)

The right for women to live and raise their children in a healthy house depends on government housing policy (Children's Commissioner's Expert Advisory Group on Solutions to Child Poverty, 2012). At another level, health services and health professionals have access to knowledge of funded services that provide home-visiting asthma education and support, services that assess, and advise on the health of home environments, that connect whānau to insulation funding and appropriate heating for those on lower incomes. Fran had not been given information about asthma as a disease process, nor advised about environmental triggers, nor connected to community services funded to promote healthy housing from her medical centre. "It was just sign away a prescription, 'Here you go, see you in a month to let me know how it's going.' That's it. That's what they always say. I'm like, 'Far out.'" (Fran, Int. 1)

By the second interview Fran did have a positive story about the medical centre and while she didn't like not knowing who was going to attend to her or her children, a doctor they had not met before provided the care and support they needed: "I saw a [locum] doctor there for the first time...I felt really confident and safe.... He was the first doctor down there that's ever done a proper check on my baby and understood there's something wrong with him" (Int. 2). The baby was thoroughly checked and treated, they stayed under surveillance at the medical centre until the baby had improved and settled, and they left with a short-term plan:

Even though we had to wait there a long time it was so worth it.... He also wrote me out this thing for the hospital just in case when we came home he got worse. I felt really taken care of for the first time. It was cool; it was good. I wasn't worried at all. I came home feeling good and my boy was happy. He was holding his food down; he didn't have that choking cough like he couldn't breathe. It was awesome. (Int. 2)

Safety for Fran was health checks, support and information provided by the medical centre and home-based services, for herself, her children, and about their living environment; healing spaces that networked and connected.

Systemic issues of overcrowding, insufficient space, and the rostered and rotating nature of staffing in emergency departments were implicated in H's suffering experienced during at least four repeat visits over three months. H, who is a grandmother, contrasts public and private spaces and the inappropriateness of being medically assessed in a corridor:

...diagnosed up the corridor (Int. 1).... [a] degrading.... awful space ... everybody's walking past and looking (Int. 2).... And that for Māori women, or for any woman is quite degrading, cos people kept going past you, and you know when you are laying on a bed at home that's your private area.... It's not nice not knowing what's wrong with you as well. (Int. 1)

H would try and stay at home with the episodic severe pain to avoid another unsatisfactory emergency visit, until her husband would intervene, encourage and carry her. Eventually H was referred to a surgeon. The delayed diagnosis may have been attributed to in part by the public corridor space hindering appropriate assessment, by staff-stress working in overcrowded conditions where there were not enough cubicles. H didn't know why she was never prioritised for a cubicle, perhaps an example of racism, of being 'bothered'. She collectively blames herself, her whānau, and other Māori with whom she associates for not being able to afford medical insurance to access private, and potentially more immediate health care, so they had no choice other than the public system. "I guess it goes back to ourselves, too, if we were smart enough to have our own health insurance covers. But a lot of us can't afford it, it's quite expensive" (Int. 1). Her visits were not followed up by primary health investigations and it appears no health professional had an overall and ongoing relational view. Eventually she was referred to the surgical team for investigations as an outpatient and then received successful surgery as an inpatient. Her experience of the surgical team's care was markedly different. H says of the team leader, "You couldn't wish for a better specialist once they found out what was

wrong with me” (Int. 1), and H feels she was given their time and attention, explanations and information, which has made a difference to how H now views the whole episode:

You know they really took the time out to make sure you were all right; they took the time out to talk to you, and tell you what was wrong, explain everything to you. So that sort of... not balanced it out, but made me feel a bit better. (Int. 1)

Systemic issues of staffing, space, and inequitable cost of health care as experienced by the women, affected their health and health care engagement. Culturally safe practice occurred where understandings of the woman’s unique space and difference were structured into competent care. Then a sense of wellbeing was possible.

Systemic exclusions: “I never had any of that support, never”

Some stories suggest systemic issues that fail to take account of the concept of difference in culturally safe care. The women described experiences of rotating staff affecting relational care, contested hospital beds, insufficient informational support, universal programmes that fail to cater to need, services experienced as judgmental or assuming socioeconomic ability to access. In the first story the woman experienced a rotating midwifery care system as relationally disruptive in a vulnerable and anxious time with disempowering consequences.

Fran was with a community midwifery group to deliver in a public hospital space, but she never knew which midwife she was going to see. The delivery processes went well, but Fran felt she was discharged too soon after the baby’s birth: “Far out, that was like a ‘had-your-baby-goodbye’ thing” (Int. 1). Fran experienced her care as being rushed and insufficient, baby was checked, Fran was not and she still regrets she wasn’t supported to breastfeed:

I had different people again. The birth and everything, that went all well. I was taken good care of there; it was just afterwards. Afterwards it was like, ‘Okay, you can go home now’ and I’m like, ‘mmm, is my body okay?’ But there was no checks or nothing to see if I was okay. It was just baby’s good enough to go home now but I didn’t get a body check or nothing. They didn’t get time to help me to learn how to breastfeed or anything... so I never learned how to breastfeed my kids. I never got done properly in hospital like to teach me properly. So I just didn’t want to do it. Like I tried the first time and that and I didn’t get enough help at the time, so yeah, it’s a pity ‘cause my kids have missed out on breastfeeding. (Fran, Int. 1)

Fran had been offered antenatal classes for her first baby in another place, but not for subsequent babies in her current place. She attended two exercise classes before her first birth but didn’t feel the need for any more as she felt she was experienced with children. So Fran

never received any information about her own body or any preparation for breastfeeding, which would have compounded the effects of the lack of information and assistance in the postnatal ward.

It was all the exercising thing and that, how you move your body around on the floor. I only went to the first couple of classes. I had a lot of experience with babies and kids; I was like the baby sitter in the family. So I didn't do no parenting courses or nothing. Once I had my daughter it just fell into place that I'm a mum now. It fell into place, yeah. (Fran, Int. 1)

Fran's understanding of antenatal preparation may reflect the framing of antenatal education by health professionals and funders. It would seem the differing needs of young Māori women are assumed rather than given central place in the planning and delivery of pre-birth preparation and support for parenthood. Most of the participants in this study had not received antenatal education services; pregnancy support from agencies was limited, too. For Louise the options for antenatal classes meant being with older, expectant women (likely white), and she was in a difficult space and place. As a pregnant mid-teen, estranged at the time from her whangai parents, asked to leave school, living at her younger boyfriend's family home, Louise was burdened:

In my mind I thought the older women would judge me.... I was already getting judged by other girls at school and it was getting a toll on me where I was having fights. Therefore, the principal asked me, politely, if I would like to leave. He had given me a Leaving Certificate, yeah. (Int. 2)

Louise did not receive any other help from school and she appreciated the on-going support in the relationship she developed with her midwife, "She supported me in that she came frequently" (Louise, Int. 2). When her "ex-mother-in-law" (Int. 2) tried pressuring Louise to have an abortion against what Louise felt were her Māori beliefs the midwife told her:

... it is your decision what you want to do. I think you already know. You are young but ... if you want this baby then you have the baby and I'll be here to help you and support you and guide you.' (Louise, Int. 2)

When the midwife's visits concluded well child services began. Louise felt she was doing well with her baby considering her age, living situation, lack of support from her boyfriend and his parents' housework expectations. The visiting nurse didn't comprehend her circumstances; Louise felt judged.

Its just things like, ‘Oh, she’s a bit underweight.’ Okay, so I give her the breast plus the bottle, and she comes back a few weeks later and says, ‘Oh, she’s a bit over weight.’ I’m like, ‘First you tell me she’s underweight, now you tell me she’s overweight. What do you want me to do?’ Then she was looking at me like, oh, just her expression and like I don’t know how to look after my baby, yeah.... [Louise thought to herself] ‘If you really knew, at the moment I think I am doing a good job.’ (Louise, Int. 2)

Young parent, Māori and poor, Louise had no access at the time to appropriate health, social, educational assessment and intervention to inform and support her own welfare, development and parenting. “I never had any of that support, never, I had to do it on my own” (Louise, Int. 2). Doing it on her own meant resisting the antenatal classes on offer as prejudicial to her own needs and wellbeing. It meant keeping going even when she perceived judgmental attitudes towards her baby-care efforts, receiving nothing to promote change. Within months Louise was low-wage employed to support her baby and boyfriend; within months Louise was pregnant again. Resistance to engage with health care at times may be self-care in the face of health professional attitudes, othering, and one-size-fits-all programmes such as the antenatal programme on offer at that time and in that contested space.

The effects of poverty on the health of women and their children are inherent in Shar’s story of the anxiety and powerlessness following a baby’s hospitalisation. Paediatric admissions have a three-day telephone follow-up service on discharge that is run by paediatric nurses. The baby was fine the first day after discharge so Shar was told to ring if she needed and the nurses didn’t contact her again:

I thought the follow-up was three days or we’re meant to ring them. But especially when mums like myself don’t have a landline, how am I supposed to ring them? ... Not everybody’s got money to buy credit on their phone. (Int. 1)

Shar was also distrustful of the telenursing and medical services feeling she had received conflicting advice; that her baby’s condition at times had been under-diagnosed: “...what I’ve been through, its like, ‘Who do I go to, who do I trust? Am I getting a straight answer or am I getting the routine of what they do?’ “ (Int. 2).

The women describe negotiating health care from positions of poverty, geographies of exclusion. While the medical model for them has been primarily individualised, they remain dependent on a system that frustrates them in their disempowerment. A culturally safe service would enable access by taking an appropriate life course (Barnes et al., 2013; Ratima & Crengle, 2012) and team approach to the socioeconomic determinants of health.

Spatiality and time: “She didn’t have time...”

The meaning attributed to place (P. Jackson, 1994) may be affected by the relationship between spatiality and time (Kearns & Gesler, 1998). Appointments that are rushed impact the health professional/whānau relationship affecting meaning of place. Similarly, not having/making time to investigate a health history influences meaning of place for the one whose health history is ignored. For one woman, resistance to ever re-engaging with a place, a particular medical centre, is the self-care effect of the gendered and perhaps racialised nature of the appointment time schedule for herself and her partner, a response that was at the expense of her own health, influencing her own “life chances and opportunities” (Patel & Rushefsky, 2008, p. 23). Pam and her partner had been parents since their mid-teens. One time, after several children, they reviewed their relationship and made the decision to go together for sexual health checks at their local medical centre:

My kids’ dad and I went in to get smear and tests done and I asked for a female doctor to come in and he said, ‘No, there’s not any available.’ So he did my test, he did a smear, ... rough as, uncomfortable, and when he walked out it was (kids’ dad’s) turn. Then a female doctor came in and did his one. I thought, ‘I’ve just asked for a female ... it’s uncomfortable having a male because they don’t know what it feels like and they’re rushed.’ ... We both looked ... at each other and looked at her, ‘Where’s that male doctor gone? He can do his, he just finished doing mine.’ She goes, ‘Oh no, his hands are full at the moment. He’s gone to do another case.’ Then I said, ‘Well, how come you didn’t come in to do mine? I asked specifically for a female and you didn’t give it. You’re coming in to do his one, what’s up with that.’ That felt really weird. We moaned to each other and then we moaned at her. I wasn’t happy with that and I didn’t bother going back ever. (Pam, Int. 1)

The couple protested to the doctor but they didn’t take their complaint further, for example, to the manager or the Health and Disability Commissioner (2009a; 2009b); they didn’t know they could, they didn’t know how; the medical centre had not told them of their right to complain, nor of the process. The medical centre could be argued as having a culture that did not allow space for Pam and her tāne (Mikaere, 2011), of having a geography of exclusion (Sibley, 1995). They did, however, find the medical centre thorough when examining their children.

There were other places, contested spaces, uncomfortable for the participants as Māori women, or where they felt their needs were not met. Tairua said her doctor was “pretty good” (Int.1), but several times in the interview she talked about rushed consultations for her health needs where she didn’t get

the information about herself that satisfied her, and she had never been invited for a smear, either by post, phone, or in person, when attending for herself or her whānau.

I just wanna know more about myself instead of just going there and finding out what's wrong with me and that's about it and then getting my prescription.... There've never been mails or any like phone calls or anything for me [about cervical smears] from my doctors or anything. (Tairua, Int. 1)

The cost of appointments and doctor attitude affected Louise's health care engagement when she relocated from a rural area and registered with an urban medical centre. Subsequently, the contested space for Louise as a Māori woman with complex health issues affected her ongoing treatment needs:

I've delayed some of my health care with my general GP before I went to [marae clinic]. I just didn't like the service that I was getting from the [urban] Medical Centre... plus I couldn't afford the fee that they were asking for... the doctor there wasn't understanding of the circumstances I was in, so I felt that I wasn't getting the best care so I changed doctors, medical centre, yeah... The doctor's attitude, because I had transferred from [rural town] moved to [urban area], she didn't have time to look at my file, at my medical notes. So therefore, every time I went to go see her she would basically misjudge me. (Louise, Int. 1)

It wasn't the gender of the general practitioner that made the difference for Louise; it was her perception of being in a place of not being judged, of understanding, being listened to, given time; of thoroughness in assessment, diagnosis and appropriate treatment plan and support; implicated is the affordability of service.

In the [rural] Medical Centre... he [GP] wasn't judgmental, he had more understanding, he even had time to listen, and he even said that he went through my medical notes ... and he knew that I wasn't well enough to go to work. So he was the one that put me on the sickness benefit... [recognising] all the traumas that I have been through in my life and because I have never had counseling for it. So he understood that, 'You need to be healthy in the mind and in the body, before you can go out to the work force.' (Louise, Int. 1)

The rural doctor referred Louise to specialist services, made healing connections:

That's when they diagnosed me with post-traumatic-stress-disorder, major depression, stress and there was another diagnosis that they gave my doctor, ...alcohol foetal syndrome... because I'm adopted, my birth mother was a heavy drinker right through my pregnancy. I

didn't know that until the psychiatrist had brought up other files of my birth parents and their histories. (Louise, Int. 1)

Louise appreciated the care and support from those specialist services at that time and confidently told me,

I'm not a drinker... when I was a teenager, I drank, yeah, and there was some traumas that's been in my life, I drank heavily, yeah. It wasn't a nice sight ... I don't have that anymore, I haven't had a sip of any sort of alcohol for three years now. (Louise, Int. 1)

A team of health professionals had enabled Louise's agency; one doctor on her own in a rushed consultation alienated Louise by othering her, ignoring the context of her life.

Time-critical decision-making influenced Marie's mother, in the absence of relational support, to make a treatment choice she later regretted. Marie reported how the surgeon, appearing indifferent to or unaware of power and difference in the interaction, presented to her mother the diagnosis and treatment plan for breast cancer on her fifty-eighth birthday:

[The lump] was underneath her arm.... She thought it was a boil and she went to the doctors for it and it wouldn't go away (Marie, Int. 1) '...that's how he said it to her. 'We'll cut them off... we'll take the breasts off.... We can't muck around you know'.... Information was coming at her but it wasn't sinking in here, because all she heard was the word 'cancer'. So it's like, how do you then, after telling someone that news, help her through just that word? And just knowing that that word to all of us means, 'I'm going to die soon', you know, that's all that says. After that you're not going to hear all the other stuff. (Marie, Int. 2)

Contested spaces may be seen as gendered, racialised, time-challenged, and difficult to access from the socioeconomic position and context most of the women occupied. Where power relations enable through information, support, a team approach, and appropriate and timely referral where necessary, connections and networks led to healing places of inclusive spatiality and time. In the next section the women's stories tell of the meanings of their bodies as Māori women, of the body as geography, the body in geography affecting health and health care engagement.

Body as geography, body in geography

Body as geography in a whakapapa of health enables the women's feelings of different public and private places and spaces, connections and networks to be viewed as experienced by them

as women and Māori. The sacredness and mana of wāhine (August, 2005) is considered in medical spaces and places and in private and public places, and spaces of abuse.

Gendered body and place

Dolores contrasts a contested, non-relational and gendered service where she wasn't given information with another more negotiated service where she is able to have her say about her body; a culturally safe, potentially concordant (McKinnon, 2013), therapeutic relationship. The contested place is also her gendered, racialised and othered body, receiving a service she found insensitive, disrespectful, authoritarian, and concerned only for the physical. Her previous belief in the doctor knowing it all she sees as coming from her parent's beliefs, as Dolores describes:

The doctor... was a male, wasn't very sensitive, wasn't talking to you, 'Oh, this is what I'm going to do and the reason why I'm doing it.' So from my point of view the doctor had no respect for me... today things have changed for the better, in a sense now that you'll know that you can have your say, 'No, this is how I want it done'. So prior to that, the doctor had the whole 'shibam', what he said went and that was it.... Well I suppose that [belief in the doctor's authority] would've come from my mum and dad... 'Everyone has a role to play,' and the doctor to do with your body and health, should know it all. But I suppose physically, yes, but spiritually, and mentally, no, he didn't have that capacity. (Dolores, Int. 2)

Lack of information about a significant and intimate procedure compounded the anxiety Makere suffered when presenting at a hospital clinic: "Nobody told me... I was so shocked" (Int. 1). The gender of the doctor may also have been implicated in how she felt as Makere said, "I turned up with a male gynaecologist and I don't know, I just felt uncomfortable with him. Nothing against him..." (Int. 1). However, when he asked if the three students who were already in the room could observe, Makere resisted:

And then the other thing that happened after everything else that happened was that he had three students that he asked if they could come in. I thought, 'Oh no, this is just the last straw for me.' So I said, 'No, I don't want to have this if they are going to be in here, 'cause it was like, two women and a guy... it's just like... stink 'cause they're standing there. (Int. 1)

While permission to observe a sensitive procedure was requested, it was expected Makere would acquiesce as the students were already in her space; the expectation was from a gendered and hierarchical position of power impacting subsequent health care engagement, jeopardising

life chances. Makere never attended follow up: “You feel like you’re exposing everything about you.... You know, to be honest, I decided I wasn’t going back again after that...” (Int. 1).

The contested geography of the gendered body affected health care engagement for cervical smears for H through lack of information about the procedure, the respect she has for her intimate body areas and the gender of her doctor. Her access now to a marae-based service for information, a female nurse smear taker, and a recall system means she doesn’t delay, as she explains:

Now, I must say I did... [delay cervical screening]. Now that we have it on board at the marae here, I don’t miss it now. You know. I go when I get my recall, only because I’m now educated in that area.... I was okay when the nurse did it. But I don’t like him (*emphasised*) looking there. (H, Int. 1)

The meaning inherent in geography of the body for H affects her decisions about meaning of place, about service and gender choice, about body in geography.

Although Shar thinks having a cervical smear “ must be a good thing” she has delayed:

“ ... because I get too embarrassed. I’d rather not show someone my insides. I don’t know if it’s a trust issue, or just embarrassed actually” (Int. 1). Shar was anxious when she was examined for heavy vaginal bleeding by a male doctor:

... but I had a female nurse there and I was just trying to look away and not think of a man’s doing it. But at the end of the day its like, ‘Well, you’re there for a reason; you are a doctor. I’m sure you’ve seen plenty more,’ but sometimes you are embarrassed. (Int. 1)

By having the support of a female nurse, Shar was able to rationalise and proceed with the examination but wonders if events in her past contribute to the anxiety and embarrassment she feels with the trust necessary to expose what she sees as an intimate area of her body:

I was with a partner for a very long time before I met this one here. Not once did I let him go there or see it.... I don’t know whether it’s due to my past histories. It could have been. With this partner here it took me a while, yeah. I trust him now. Before I didn’t trust anybody. I know I need to go again for a smear test, but it’s like get the courage up and get over it. (Shar, Int. 1)

When Aroha was referred to a radiology service for an ultrasound scan, she went with her

children before her work and their school. A young male radiographer attended to her, which she commented about but was not offered a gender choice. She justifies continuing because his manner and explanations of the procedure produced a comfortable atmosphere for her; Aroha wished to be fair to him and she wanted the job done so she could continue with her day.

I bought it up that, 'Oh, its different that you being a male.' He says, 'Oh yeah,' but he didn't offer me a woman ... you know the atmosphere I suppose it wasn't even like that.... he was explaining it all [to] me. There was no time to worry ... But he was only young and I mean, well, give the guy a chance.... I don't want to be difficult. I just want to find out, get it over and done with, get the kids to school and go to work, sort of thing. (Aroha, Int. 1)

Although geography of the body was significant to Aroha, the manner of the service she attended enabled her to remain engaged, regardless of the gender of the radiographer; it was a therapeutic place.

The gender of the surgeon mattered for Anne when she had a problem that required surgical intervention on an intimate area. Anne was "weary"(Int. 1) of the failure of two successive male surgeons. The third time, a woman surgeon successfully used a different technique. Anne found the woman surgeon identified with her as a woman, and appropriately for Anne, before the surgery said *karakia*.

The third time that I went in for the operation there was this little woman surgeon. I gotten a bit tired of it by then... the specialist had been a man every time.... [The woman surgeon] said, 'I suppose it's a man-habit they do it like this every time... they don't' know what it feels like.'... So she told me she was going to [do] this other [way], the way you stitch it all the way around.... She had *karakia* with me just before the, the thing. And I felt really good about that. (Int. 1)

Anne attributed outcomes of intimate surgical interventions to gender, and eventual *karakia* made connections in that place for her: a complex *whakapapa* of health.

The intimate mystery of an inhabited pregnant body and a pregnant body inhabiting space is in Ani's story. In her first pregnancy Ani and her partner heralded the pregnancy to everyone then experienced the contested nature of the surveillance of the pregnant body. "It became a really big deal and a lot of focus put on it and myself and my partner at the time" (Int. 1) so that when she miscarried at three months it was public news. Several years later, pregnant again, Ani this time wanted to be in control of her body, her own space. Her new partner said:

‘It would be a good idea just to have it between us.’ So I didn’t go to the doctor. We just carried on as normal. I was really healthy; I was really responsible nutritionally. I exercised and I just didn’t feel like there’d be a need.... I wanted to stay in my own space with being pregnant.... I really did like it that way. (Int. 1)

Ani and partner were similarly quiet about Ani’s third pregnancy, “There was no one to say what to do, yeah, even the birth, because I wanted home births” (Int. 1). The privacy and ownership she wanted for her own body contrasts with witnessing a family member with toxæmia and other complications in labour in a large tertiary urban hospital:

...a lot of intervention ... it was quite horrible ... there were doctors everywhere. They ended up giving her [an] emergency caesarian, and it was all happening around her quickly and she was just lying on the bed, and it was not what I wanted.... so impersonal and so clinical.... I was actually scared of being in the hospital ... and have other people take control of my body and what was going on, and dictate to me.... I wasn’t scared of being home by myself. (Int. 1)

While Ani at one level understood the life-threatening position of the family member and baby, at another level the hospital became a large and public health space which she saw negatively as impersonal, taking control, eliminating choice, dictating proceedings; a place to be “scared” to be. Remembering being pregnant, Ani expresses her feelings about congruence with the space and place the pregnant body inhabits and for her it was keeping the news of the pregnancy between herself and her partner, not consulting the doctor until the pregnancy was well advanced, and choosing to give birth in her own home space.

Geography of the body influences spaces and places women attend for their health, while the gender of the health professional influences, or is rationalised to enable, health care engagement. When relational qualities and the giving of information and support are characteristic of health care, on going engagement is enabled. In the next section, environments, private and public are not always safe, and some participants told in their stories of the gendered nature of abusive space and the effects on their health and health care engagement.

Abusive space: “It’ll never leave you, aye”

Geography of the body links to all forms of violence, throughout the lifespan and beyond. Violence is inherent in colonisation and as seen in the previous chapter, bodily remembering embodies historical trauma. In this section various forms of violence, as told by the women, have affected their health and health care engagement. Some experienced violence pre-birth with ongoing alcohol and other drug abuse, as childhood neglect, and as physical and emotional trauma. Some experienced violence from

a stranger, in dating and intimate partner relationships. Environmental and physical poverty are linked with increasing risk to women in the urban environment (Meleis, 2011). The gendered and racialised nature of poverty increases exposure to different forms of violence as women take the major responsibility to care and provide for their families (Mwangangi, 2011). Patricia, a current survivor, says of violence, “It’ll never leave you, aye. One memory, aye.” (Int. 1)

Louise, another survivor of intimate violence, describes the difficulty presenting for a cervical smear with the bodily remembering of the arranged date with a stranger in a public space, and the rape, effecting in the years following, her health and health care engagement:

I’ve put off a lot of smears, heaps, only because of the trauma that I’ve been through ... twelve years ago ... I was badly, severely raped. Down below was severely damaged and it’s hard when I go for a smear. I tend to tense up ... my whole body tenses up as soon as I am due for a smear. I get uncomfortable when there are other things inside me. That’s why I have put off other health things. That’s another subject why I don’t talk about it. (Louise, Int. 1)

Aroha has been attending the same medical centre that her parents attend since her teens and her general practitioner knows several generations of the family. The doctor also sees Aroha’s partner whom she describes as “... a bit of a ruffian that one. Bit of a ‘Once were warriors⁴⁴’” (Int. 1). Caught up in the violence cycle over a number of years, Aroha has appreciated her doctor’s awareness and care, and his thoroughness in checking her. Her children like him, too.

And he still does ask about him because he knows it was an off and on relationship for probably the last um how many years...? He just double checks me making sure I’m all right you see.... I think...how thorough he is. We just love Dr. [name]. Like when we see him down the road they’re [children] waving out, they love him. Cause he’s helping us, yeah, when we’re sick. (Int. 1)

It’s not clear in this study if her general practitioner ever identified other agencies that could support Aroha and her partner to address the violence in their lives and the poverty cycle in which they were trapped, or whether the care was limited to a medical centre consultation. The medical centre was, however, a safe space for successive generations of Aroha’s whānau.

Patricia’s story has several interweaving threads of environmental effects on her health.

⁴⁴ The title of a 1990 book by Alan Duff and a 1994 Aotearoa New Zealand film depicting urban Māori disrupted from their iwi, hapū and whānau roots, living in poverty, and caught up with gang and domestic violence.

Beginning chronologically, Patricia was raised in a home where after the death of her mother when she was very small, her father "...drowned his sorrows in alcohol. He was a bad-arse drunkard.... straight after my mum died my older [sibling's name] got taken away from my dad and that really got to him" (Int. 1). She was "eighteen" (Int. 1) when she first became a mother, experienced partner violence, and now whānau estrangement. Patricia describes the dilemma of the abusive space she finds herself caught within:

And then I started to get into that stress, stuck in between, and my mind was stressed out. My body was frustrated. I didn't know whether to go here or there. I couldn't leave the father cause he's the father of my kids. I couldn't leave the family, that's my family, so and I'm still stuck in that. I don't know, my family's turned their back on me.... Cause they don't like the father to my kids.... They know what he does to me. (Patricia, Int. 1)

Patricia's health care engagement has been a disjointed network of spaces and places, with missing connections. When questioned about antenatal care Patricia asked, "What's antenatal care? That's the thing. I hardly ever seen a midwife. She'd make appointments but never come and see me on those days" (Int. 1). Patricia didn't know about any antenatal classes to attend; she had been to a doctor near the beginning for each pregnancy.

Patricia appreciated her postnatal midwife, "She seen me all the time. The midwife that seen me after I'd given birth, she was a good midwife... On her last day she'd brung me a box of chocolates" (Int.1). The midwife referred her for well child services but being away from home when the well child nurse visited was possibly due to Patricia keeping herself safe in a violent environment: "Plunket's⁴⁵ been good. I've been to see them and when they've come over home, I'm not there.... I'm hardly ever home" (Int. 1). When the baby was overdue vaccinations the medical centre referred the baby to KMHSS outreach immunisation service who vaccinated the babies and referred Patricia and her whānau to KMHSS Family Start worker and Mother's Group for ongoing support.

It was at KMHSS Mother's Group that Patricia heard about postnatal depression (PND) and baby blues from a guest speaker. Another attendee told her story. Patricia recalled: "When I was listening to it I thought, 'Hey, that's what I was going through' and, 'Oh, gosh, I didn't even know that I had that' (Int. 1). Patricia had learnt from her family 'It's the family you need to make you better', and she saw the medical centre as they did, "the Pākehā system" (Int. 1). But Patricia at the time did not have family support. She asked her Family Start worker for help

⁴⁵ Mainstream well child services (www.plunket.org.nz/).

with a safety plan and the support from Mother's Group was a good day each week; it provided friends through the week:

Having friends to talk to about it is helping me out... heaps.... Mother's group is a help cause the Mother's Group is so beautiful, you know. They are, everybody there is so nice. I always leave Mother's Group so positive, so happy until I go home. And then my day just falls back down. Sometimes I don't look forward to going home. (Int. 1)

Home-based services and Māori-led initiatives are enabling Patricia to access some of what she needs for herself and her children in an environment of poverty and intimate partner violence and whānau disconnect.

Angel carries hurts from neglect and rejection as a child, from ex-partner abuse, from family observing one incident and failing to intervene. It was compounded by family suicides, and other traumas and Angel had learnt to use alcohol in that abusive space to try to solve how she felt:

When you look back at your life 'Oh my gosh, that was no good, why does my mother do it to me?' To me it was she loved everybody else but not me... I did not know that neglect wasn't right until now (Int. 1)... Alcohol ... all that come first in their life, my [birth] mother's life (Int. 2)... I got beaten [by ex-partner] in front of my real brother and my birth mum and they just stood there and watched... He had big cap boots on and he just beat me till um I was black and blue and I think that's why I don't want to have that relationship with them any more. You know I'm hurting still, although it happened many years ago. It's still in there, and that's the burden I'm carrying (Int. 1)... I have come a long way and I know alcohol doesn't solve nobody's problems, it just makes things worse I think, not better. So I'm glad I wised up throughout my years of being a mum. (Int. 2)

Possibly the violence Angel had experienced in her life contributed to what she now recognises as PND or baby blues; she felt distant from her birth family, her partner was working long hours. Angel told her midwife she was "crying for nothing," (Int. 1) and was disappointed with the outcome:

She fobbed me off, 'Just go and see the doctor and get some pills and you'll be all better'.... that was her answer.... I was really upset with the midwife and her services and her strategy not to help me but to fob it off with pills, 'you'll come right'.... Midwives when they take care of you they actually don't fill you in. I never got offered antenatal care. (Int. 1)

Angel doesn't believe in taking pills to fix problems. She doesn't want to become an addict "statistic" and act in "a bad way" leading to her children being removed from her care (Int. 1). Some months later at the KMHSS Mother's Group Angel began to attend, a guest speaker administered a survey and Angel identified as suffering from PND/baby blues.

It was a really tough time in our lives and especially for my husband and for my kids.... The dad was working a lot... I had to persevere with my child... I've got no family here so it was all on me... I'm just so pleased that I finally sought help and I guess that what made it easier was when we had a guest speaker [at Mother's Group] coming in to talk about post natal depression/baby-blues.... (Int. 1)

The support of the weekly Mother's Group was enabling as was speaking her truth in the first study interview. By the second interview several months later Angel had been able to discuss with the same midwife, re-engaged for a new pregnancy, how she had felt 'fobbed off' by her previously and about her aversion to treatment by pills. The midwife's apology and new knowledge of how to meet Angel's needs contributed to positive changes in the landscape for Angel.

Now I've got the same midwife as I did with [baby's name]. So I've made her aware of what we went through... of not fobbing me off to the doctors... I think because she had too many clients ... so we've come to an understanding about communicating with each other... I actually shared with her about our little study just on the postnatal depression and the midwife services. Now she's coming around home to do all our check-ups.... So now I know that I'm not going to be putting off appointments. I'm going to get myself fully checked and carry-on. We've got a really strong relationship now and I'm really happy about that. (Int. 2)

The women told stories of inhabiting bodies that experienced violence when disempowered as gendered, racialised and othered bodies, and the effects on their wellbeing were life long. There were gaps in health services engaging and effecting change for the women, while a multidisciplinary and community based approach was culturally safe and had meaning.

Conclusion

Places and spaces in the landscape of a whakapapa of health have connections and networks. The women describe places that were inclusive and spaces where they were othered, stories of geographies of inclusion or exclusion, of gaps in networks and connections. Contested spaces were places of dis-enabling power from systemic health service and or individual factors, such as constantly revolving staffing affecting the ability to establish trust and the development of

good relationships, connections, and networks. Rushed consultations and othering, not feeling listened to, being given prescriptions without a whānau, or home environmental assessment or other socioeconomic determinant of health referral, were spaces of exclusion (Sibley, 1995). Competent and respectful health care interventions, feeling supported and informed, connected to networks of wellbeing, promoted wellbeing for women and their whānau.

The private nature of the gendered body, at times experienced in health care interventions as racialised, and marginalised, impacted health care engagement jeopardising life chances. Where there was mana wahine, there was health-promoting engagement. The geographies of various forms of abuse from pre-birth to current experiences of intimate partner violence were disruptive, life threatening, with ongoing effects. In the next chapter geographies of wellbeing are developed as the women remember back and imagine for the future healing spaces and places, networks and connections; remembering and imaging a therapeutic landscape for themselves and their children, and at times for generations future.

Chapter Seven: Therapeutic landscapes: Remembering and imagining an ideal

Landscapes, to the reflective viewer, meld times past, times future, spaces, places, connections and networks into a therapeutic ideal of healing and wellbeing. The women remember past experiences of health and health care engagement, their own and that of their whānau and in their reflections they imagine therapeutic landscapes (Casey, 2000; Gesler, 1992). What the women bring to their assessments of services and their therapeutic ideal of healing and wellbeing is profound. It can be understood in the nursing theory of Kawa Whakaruruhau with categories of power, difference and subjective assessment (Ramsden, 2002). They each bring their “personal interaction[s]” (Anthamatten & Hazen, 2011, p. 162) with historical, societal, and environmental factors across different landscapes, physical, metaphorical, traditional and everyday (Gesler, 1992). Their remembering and imagining creates therapeutic ideal (Gesler & Kearns, 2002) informing nursing practice, providing practical suggestions for health professional practice and health care providers. In the therapeutic landscape health care provision is relational, competent, and systematic, and the women and their whānau are central to the health care team. There is a focus on the social determinants of health, the giving of information and support, and the fostering of a mindset of self-care, for self and for whānau.

The therapeutic landscapes the women imagined for themselves and their children were at times even for their children’s children, Māori youth and their parents. The women were serious about their role as teachers and guardians of future generations. Remembering their own life journeys, and those of whānau before them, the women reflect on knowledges needed by their children for the way ahead. Remembering silences about bodies in generations past, they imagine how to find voice to prepare future generations. Their stories at times reveal the role of by Māori, for Māori services in health care participation (A. King & Turia, 2002). In the first theme the women recount stories where they felt welcome and at the centre of the service, or stories where they felt disempowered and they imagine what needed to happen so they were empowered and centred.

Renegotiating place: From ‘other’ to centre in health services

Sometimes the stories the women remembered were of being othered, of being disempowered, so they imagined renegotiating place from the margins to being in a place where they were central and the health care was for them. Introductions to a health care provider often determined the contour of the whole encounter.

Contours of encounter

The manner in which women and their whānau first encounter a health service and the people that work there may determine the contour of the relationship. The manner of greeting establishes therapeutic intent and determines the potential for the women to feel culturally safe, for the health service to be a welcoming environment, a healing space. Being given appropriate explanations and information is respectful. One mother with a number of small children describes contours of encounter at her medical centre that are disempowering to her as a mother, where the doctor takes charge before she has a chance to settle her children, where neither she nor her children experience a welcome and where she leaves lacking information. Pam says they are routinely greeted by their doctor in a “rude” (Int. 2) tone with, “ ‘Sit here, sit there’ ... ‘What’s the problem today?’ ”(Int. 2). Imagining a culturally safe ideal Pam acts out how she would like to be addressed demonstrating a welcoming, smiling, amiably said greeting instead: “ ‘Hallo, how are you doing? How can I help you?’ ”(Int. 2). As their mother, Pam wants a chance to be able to seat her own children and pleasantly imagines: “I’ve got to put one kid down first and then the next.... I’m automatically going to go, ‘Here you go, you know, sit you over here, sit you over there’ ” (Int. 2). The consultation feels rushed and inadequate to Pam: “Have a quick look, ‘There you go, away you go.’ ‘Oh true, short, Bro’ ” (Int. 2), and Pam imagines having time to have explanations instead of having to wait to have her questions answered at the pharmacy: “It’s not until I get to the chemist, and they fully explain” (Int. 2).

Pam tries to decipher the barriers in the doctor’s manner: “I’m not sure if it’s a race thing, or whether he just doesn’t like kids in general” (Int. 2). In the two years Pam and her children have attended the medical centre, four times in the weeks prior, the doctor had not checked what was due, and nurses at the medical centre were invisible: “...the smears, I didn’t even know about that until I received a letter from you that I was... overdue. I didn’t find out that the kids were overdue for their immunisations.... No, never spoken to a nurse, not” (Int. 2). In Pam’s ideal therapeutic landscape she would have a welcoming and pleasant general practitioner who allows time to listen, likes children, empowers Pam as a mother, and explains the diagnosis and treatment fully. Pam would attend a health centre that has a team approach to inviting Pam and her children for timely health checks and immunisations, information and support, and is positively inclusive of ethnicity and socioeconomic circumstances in the geographical locale.

Having a nursing service that centred Louise and where she felt welcomed enabled her to overcome barriers and provided Louise with a healing space. She remembers her previous feelings about attending for a cervical smear: “I’ll hold it off as much as I can or I’ll lie cos I won’t go, cos I wouldn’t have anything up there that’s not s’posed to, that’s cos of the trauma that I had gone through, aye” (Int. 2). A nurse from a marae-based well woman service visited

Louise at her temporary shelter. Louise told how she felt with the nurse, “I was the voice and she was the ear to listen.... It took a couple of visits for me to open up to her about it, and when I told her, she kind of understood” (Int. 2). They agreed on a clinic appointment early in the day and the nurse would provide transport. “I didn’t have to wait half a day when I could have dodged.... She bought me a muffin and a hot chocolate” (Int. 2).

Although nervous, Louise felt the welcome as she entered the marae clinic: “The aura of the people, yeah, everyone around me was welcoming, ... words can’t explain how I felt that day. I was happy” (Int. 2). With the welcoming support and the information to help her over her barriers from past experiences she concluded she would readily return in the future for cervical smear screening. Louise was able to access social work and counseling services through her introduction to the marae and she concluded: “It’s a blessing, it is, because if I had that years ago, who knows?” (Int. 2). The experience for Louise of being central to the health provider and not other, the connecting of services, left her wondering how her life may have been if she had felt central to other services previously.

Dolores gives examples of ways to make women comfortable that are respectful and tikanga. The first story is about the lead-in to a health appointment, with a contrasting experience:

... not just going straight into it but to ask the person how are they? ‘Had a good day?’ ‘How are you feeling?’ ‘Are you comfortable with me?’ and just the list just goes on and on.... for me that’s how, you make people comfortable instead of going, ‘Ok, come in my office now, lie on the bed, open your legs...’ And that’s it, aye?

Interviewer: Did you have that experience?

Dolores: Yes, I have, and putting up something up there, up your whare tangata, something cold. (Int. 2)

Dolores’ second story emphasises respectful practice, again with a contrast:

You know, when I first got my breasts done [private diagnostic mammography]... I thought that was a bit cold, quick and fast, and when I just got my breast screening [publicly provided mammography] done again this year at [named] Hospital and the lady was soo gentle, I don’t know, it was quite calm in the room you know... and I told her when it finished, I says, ‘Oh thank you for respecting me’, I says, ‘I felt so comfortable’, ... she was good cos she talked me through, ‘Are you ok?’ ‘I’m not pushing hard?’ So all those, and it really, really matters. (Int. 2)

The third story is about tikanga, which to Dolores is the gentle approach of the nurse at a marae well women clinic when talking about the procedure first, and notifying the woman of the results later. “She’s really, really great...very gentle, talks to you first before...lets you know after, all the things. It’s that protocol, aye. We talk about tikanga; well that’s part of tikanga” (Dolores, Int. 2). Follow-up is respectful; it acknowledges the woman’s waiting concern even if the results are normal, as Maria feels: “ ‘If you don’t hear from us, you’re fine (*laughs*)’. It’s not... it’s that waiting period... it’s really stressful” (Marie, Int. 2). The nurse cognisant of tikanga in practice begins gently, informatively, and follows-up appropriately demonstrating respect in relationships by providing a Kawa Whakaruruhau service. The woman has subjectively assessed the nurse’s practice as culturally safe, so promoting on-going therapeutic access to health care.

The listening of encounter

In a therapeutic landscape, places of healing are non-judgmental listening spaces where the contribution of the woman speaking her story, her knowledges, her concerns, truly informs the healing process. They are places where information is appropriately given to advise about health, illnesses, treatments, and services. “Safety for me is someone I can talk to about how I am feeling and people who won’t judge you” (Angel, Int. 2). Louise experienced her new medical centre as having negatively judged her story and therefore, as unsafe, so she changed providers: “That’s my personal reason why I changed medical centres.... It was judgmental to me pretty fast” (Louise, Int. 1). Shar feels positively about the mental health care nurse at the health centre she attends: “She listens, she’s really good, I like her” (Shar, Int. 1). Fran has found she feels safe to talk to the nurses at her health centre; she doesn’t feel safe with the doctors. A therapeutic space is a listening place:

Fran: Well I feel safe and comfortable when I see the nurses more than the doctors.

Interviewer: Is that a relationship thing? Is it more time?

Fran: More understanding and they listen. The doctors usually down here, it’s like da da da da. With the nurses you can explain about your body or what’s going on. I feel comfortable when I see the nurses down here I feel safer if you can open up to someone, but because you see all different ones you can’t build a relationship with one because you’re seeing all different ones and you’ve got to explain the story again, explain it to a different one again... (Fran, Int.1). If I’m supported I feel really safe, if I’ve got good support. (Fran, Int. 2)

Angel wants to be listened to, and to be given full information before considering accepting prescribed medication. Whānau attitudes to prescribed medication, based on what has happened

to various members, have influenced her: “My family are all against having pills just to fix everything” (Int. 1). Angel says they’re scared that they’ll get addicted. She relates the common experience of whānau is that the doctor hurriedly diagnoses and prescribes medications before listening to whānau side of things, and they don’t explain about the medications to ensure understanding. Angel concludes systemic failure occurs.

‘Here’s a prescription,’ you know. ‘Go and take it.’ But not explaining what are the side effects, what will it do, you know, is it easy to just stop and not turn back and go and rely on them? I know that they are busy but it’s like they quickly diagnose you without even getting your part.... I think sometimes the system does fail. (Angel, Int. 1)

Prescribing medication without listening to, or addressing the whole person and her whānau, affects concordance (Snowden & Marland, 2012). “My family get a bit anti on their family members taking pills.... My family say, ‘Never trust a Pākehā system, they’re just going to throw you drugs and make it all better’ (Patricia, Int. 1). A therapeutic environment engages the whānau, listening to their understandings, providing information appropriately, and being relationally supportive. Rather than being medicated, Angel says, “There are always better options. Counseling’s the best; talking is great (*laughs*).” (Int. 2)

Fran was pregnant and wanted to know what was happening to her body, what was happening to her unborn child. Her concern wasn’t heard and there was miscommunication between secondary and primary health care; treatment wasn’t followed through.

I was pregnant with my last baby, I had swabs in the [named] Hospital and they didn’t even explain to me anything that was going on. They just said, ‘You’ve got this, here’s some pills’ and ‘see you later’ I was really curious because I was pregnant and I didn’t want the baby to be harmed or anything.... They just said, ... ‘Follow it up with the midwives.’ So I did follow it up with her and she reckoned she didn’t have the notes for it. So I was never treated properly for that.... And I’m thinking, ‘That’s bad communication.’ (Fran, Int. 1)

In a therapeutic environment a woman’s voiced concern is heard at each point of care and the responsibility for hearing and responding not lost in the passing of responsibility of care from one health provider to another.

For women’s wellbeing listening encounters in health care extend to their parenting role. Parents feel their knowledge of their child’s health contributes to the assessment based on being

with their child constantly. Shar has experienced taking a child repeatedly to health providers for health assessment and intervention:

Some health people are okay, doctors and nurses are okay, and then you come across people: 'They're fine, they're fine; nothing wrong with them'.... They should listen to parents more. They may not be doctors, they may not be nurses, but they know their own children especially when they're around them twenty four/seven, everyday. (Shar, Int. 1)

Although financially challenged, Shar is paying a door-to-door salesman by installments, for books for parents by an American doctor. These books enable Shar to access the knowledge she eagerly wants, and should have freely provided at each encounter with the health system. It is also an act of resistance to the disempowerment Shar has felt at not feeling heard:

Shar: It's good because they are going to help me out so I know problems with my children, so I don't sound like a dumb (*emphasised*) arse over the phone. Or sound like a dumb (*emphasised*) arse at the doctors; give doctors ideas of what I (*emphasised*) know as well, because they give me one diagnosis, then I can read up and tell them it could be something else... trying to tell them this is how it isn't. This is what I see at home. Or are they going to tell me these medical books are wrong? And yet, these medical books are (*emphasised*) written by a doctor in America... specifically for mothers.

Interviewer: And was that someone selling door to door?

Shar: Yeah... So we get eight books, volume 1-8, so I pay \$10 a week for those, \$100 a book... its worth it in that it teaches you about your whole body... the heart, the lungs, everything you want to know about... plus the medical aspects of stuff for your children. It's really good, that's why I like them. So it helps. Every parent should have one. (Int. 2)

Power and difference displayed in health professional's attitudes are discerned by the health consumer (Ramsden, 2002), and may be related to structural issues such as training, and supervision to reflect on practice, or it may be due to health centre structures that limit health professional time (F. Richardson, 2010). Non-judgmental listening spaces promote safety in Māori and women-centred medical interventions, and are experienced by the women as therapeutic, imagined as ideal. A recent and public-media way of centring the health of Māori women provided connections for some women to participate in screening services.

Private messages, public spaces: Information focused and appropriate

Well women health promotion targeted at Māori and Pacific women has contributed to Māori women connecting into screening services (Bethune & Lewis, 2009); it publicly foregrounds generic information perceived as belonging to the private and sacred sphere (Lovell et al., 2007)

via an interchange of public and private pathways. The message is viewed in the private space of home yet informs significant and supportive others to target women at the focus of the advertising to engage with publically provided services.

Targeted information via television, relational support from work colleagues, and a Māori health provider visiting her workplace contributed to Tairua seeking well women services, as she explains:

Tairua: My smear...I didn't realise we had to have it all the time until I seen it on TV and also from working here at my job.... They've [work colleagues] just been telling me, am I going for my smear...I was like, 'Oh no, I haven't been for mine yet' ... and then that's when I told you.

Interviewer: And what about what you saw on television, how did you feel about that?

Tairua: That was actually important cos the things you could get from not having a smear and checking if you're all right, so that's made me want to go and get it done. (Int. 1)

For Anne, there was a family challenge when the breast-screening message was publically aired in private family viewing time, a confrontation to which Anne eventually capitulated:

'Aren't you supposed to have a check up?' The husband and the children kept ringing in my ears.... it was on TV. 'Aren't you that age?'... 'How old are you, Mum?' 'Have you been?' 'No.' 'Why?' (Anne, Int. 1)

While Anne made the decision to attend breast screening and made her own appointment, she expresses her appreciation of another woman who was Māori that she met on the day at a church event and who, during the procedure, looked after the grandchild Anne had with her:

I booked it all myself, and I was going on my own but it was a busy day that day... I had a Māori woman with me and she was really cool.... I just shared with her that I was going for this and she said, 'Oh, I'll come with you'.... We took [grandchild in a pram] into the waiting room and she just looked after her while I went off. (Anne, Int. 1)

In her reflection on this story in the second interview Anne identifies that if she hadn't had her new friend's support she could have delayed further. However, having her grandchild with her, too, gave her a whakapapa reason to attend, as Anne explains:

There wouldn't have been a need if I was on my own ... her positive encouragement was

really helpful. 'I'll come with you. I'll tautoko you. I've had it done'.... You know that's the reason we do these things...preach to other people... 'Oh, do it for the mokos', and you don't do it yourself.... So it's important. (Anne, Int. 2)

In the exchange below, Anne indicates both how it will be routine to go next time she is due for breast screening and how she would encourage another woman by offering to accompany her to the breast screening site:

Ann: There won't be no trials about it; I'll just go and do it. It will become routine.

Interviewer: What would be important for another Māori woman that you talk to?

Anne: 'It's all right, go and do it ... Don't be silly, I'll go with you.' (Anne, Int. 2)

In H's story, a marae-based community health worker provided information about breast screening, organised the group attendance, and supported the women to the venue. The relational interaction of the women contributed to a positive event for H. While it is unknown to what extent the televised health promotion influenced H, she did describe their experience as being similar to the television advertisement with Pacific women attending well women screening together:

There was about five of us that went all at once. It was fun...we were joking all the way... every one of us came back negative, so I've no qualms about going to have it done.... I heard about it through... [community health worker]... I love that ad with the Island women on it. I think it's brilliant. That's how we are as [Māori] women, giggling and chuckling and jumping in the car. (H, Int. 1)

Māori and women-centred information gained in their private space was accompanied by culturally appropriate support; waymarks (Millar, 2000) to health in a therapeutic environment.

Consumer rights: Structures for agency

In a therapeutic landscape women receive health services from appropriate health service providers, who inform women about their rights as health care consumers and how to contact advocates for support in a complaints⁴⁶ process. Most participating women did not know how to make a complaint if or when they felt disadvantaged by the health service they received.

Anne was angry about a recurring, inadequately addressed problem: "And I did get angry, and I, and I started to write a complaint. And I hate writing, so I just gave up. But I was very upset

⁴⁶ In Aotearoa New Zealand health care providers have a duty to advise health care consumers of their rights in receiving a service; to advise consumers how to make complaints and access advocates (Health & Disability Commissioner, 2009a; 2009b).

about it” (Int. 1). Most had limited experience of receiving information about their rights as health service consumers or where to access advocates. Angel reports she experienced a marae-based service giving her a Code of Rights prior to accessing the health service. She is unaware of the complaints process at her medical centre, “I’ve never ever gotten a Code of Rights from the doctors so I wouldn’t know how to access the complaint stage” (Int. 2), and the local hospital had recently sent out the Code of Rights with a survey two weeks after a whānau member’s surgery. She is aware of the Māori advocacy service visiting her as a hospital patient but doesn’t know where in the hospital to find them herself. Angel suggests a solution to locating the Māori advocates could be a colour-coded line on the floor to their office as there are to other facilities in her local hospital:

I think being aware of what your rights are as a patient at the hospital or at the doctors even, or any service that you have with your whānau.... No point sending a Code of Rights out after the fact when [it should be sent] before the fact so you know.... And keeping myself safe, is being aware of who I can turn to. I know there’s a ... Māori advocate; if you don’t feel safe at least I know I could approach them. They could possibly sit in on one of the meetings.... ‘You can’t find them?’ ‘Follow... the coloured tape,’ kind of thing. Things like that would be a really good safety issue. (Angel, Int. 2)

Having the knowledge to know that complaints improve service, that there is a process to access the appropriate level in the organisation to ensure investigation, change of processes if indicated, and the process reported back, and having support throughout, are strong links in ensuring a therapeutic landscape. Makere was supported by a Māori health provider to submit a written breach of privacy complaint when a health provider inappropriately divulged Makere’s personal health information to another Māori woman at a different organisation to where Makere worked:

I put a written complaint in, which changed their whole processes. Like I probably wasn’t a person who would have bothered with complaining but I kept thinking, ‘Gosh, if they’ve done that to me then who else would they be doing that to?’ It made me feel really sick. (Int. 1)

The person who headed the health provider’s quality section met with Makere and her supporter from a Māori health provider immediately and again a month later for follow-up.

She headed their quality section, but she was really good. I mean, she came out pretty well much the next day to meet with me because it was, you know, she said it was a serious

breach of confidentiality, as well as my rights and stuff.... Within that month, she met with me again with a letter outlining all of the changes that had been made as a result of what they did.... At the end of the day I was pleased that they did something.... I just wanted to make sure they wouldn't do that to someone else. (Int. 1)

While a sense remains of the unsafe place Makere found herself in through the privacy breach, her complaint was a catalyst for improved processes and Makere knows to expect a standard and how to ensure quality of service if the standard is not met. Another woman feels that with her age and experience she is now able to strongly assert her position for health services as her right in a way she was not able to as a younger woman:

Well I suppose that now that I'm older... I'm not afraid to be quite forceful and say, "No this is my right". But when I was younger I was quite, quite timid and just listening to the authorities in the house saying "Oh no, you have to wait, you're not important blah blah blah." (Dolores, Int. 1)

A therapeutic landscape comprises healing spaces and places where interactions are welcoming, interventions and follow up systematic and thorough; there is information and support to make connections, to ensure standards are met, and to safely negotiate pathways. The ideal therapeutic landscape is experienced as culturally safe so there remain healing spaces and places for future engagement.

Healing environments

The women described how their vulnerability in the face of sub-optimal environments potentially affected health outcomes for themselves and whānau. The therapeutic ideal is that public hospital facilities are restful, clean, and provide support and healing time.

If they gave me an extra night I might have accomplished him feeding on me. But they didn't give me an extra night so I had to put him on the bottle.... It felt like, 'You've had your baby; we need the beds, your baby's okay. See you later.' I was not even in there twenty-four hours. That was it. (Fran, Int. 1)

Vulnerability and a lack of whānau power and knowledge to make a complaint at the level to achieve action made for a difficult time for Angel and supporters when she gave birth to her third baby: "I was put in this room where someone had just given birth ... there was blood everywhere in the bottom of the bath.... Poor (husband) was cleaning around my bed, cleaning my mattress and that, finding new linen...." (Int. 2). Sharing postnatal rooms with other postnatal women and their infants is challenging, particularly when the woman knows that with

children at home this is her only chance for rest for some time. Angel, who has an enduring illness, feels she doesn't have the power on her own to make her needs known to secure a single room; she expresses her felt defenselessness in the postnatal ward:

I'm trying to get rest and the baby's trying to get rest. It [shared room] just doesn't work.... Visitors.... Cleaners.... Midwives coming in and doing obs.... I know that if I had an advocate I'd probably get my own room, which will be fabulous, just shut the door and, 'Oh, yay,' at least have a bit of sleep, knowing that you're coming home to two other babies that need your love, too. It's kind of hard when you're so exhausted and all you want to do is sleep. (Int. 2)

Angel maps a therapeutic ideal where the health care consumer is central to the health service: "The staff to be more customer-focused" (Int. 2). The environment would then be restful and clean; assessments of available home support undertaken so that time and informational support would meet need, explanations would be given when procedures 'go wrong.'

Practices that the women remembered experiencing as safe, or imagined they needed to feel safe, were wide ranging, feasible and realistic. Welcoming, listening services that were non-judgmental, competent, informative, supportive, culturally safe, followed up appropriately and were clean, were healing places. Pathways linking healing places involved knowledge and sometimes appropriate support to traverse. The right to health means at times the right to complain, to seek a resolution to health care inappropriateness, a situation made doubly difficult when geographical and socioeconomic circumstances and ethnicity limit choice of service.

Remembering and imagining: Mapping the future

The right to life-long health involves networks and connections of appropriate relational information and support, healing spaces and places, to enable women to develop a self-care "mindset" (Ani, Int. 1), to overcome barriers such as those of bodily-remembered abuse. Most of the women recognised they needed to look after themselves if they were to care for their babies. They imagine their children, and their children's children being able to access the right help at the right time, and beginning with themselves as parents, the right information and support for whānau well-being.

Self-care: "...a mindset"

Marie has not been a woman to delay attending health appointments and she participated in this study to tell her experiences of health and health care. The experience of cancer in supporting her mother and other whānau has affected Marie's decision-making for herself and her whānau

in a positive way by attending to health concerns early, as she reflects:

Isn't it funny the decisions you make with yours when you're old because of the things that happened in your life? And pretty much to protect, aye. I think that's why I'm so adamant about every little thing that goes wrong and you know usually this will tell you something's wrong and where it's at.... cause if it's nothing aye, it's cool, you know, if it's something, then you've acted on it straight away. (Marie, Int. 1)

She also expressed how she actively role models and teaches health behaviours to her daughter:

I want to teach my daughter, too, 'cause she knows that I go to them all these things. 'You've got to keep on board, you just never know, Bubba. And if we can get to it early you know, gotta be positive.'" (Marie, Int. 1)

Similarly, Aroha doesn't put off screening. An abnormal result when she was younger, when a lack of information confused her understanding of treatment, impressed on her the value to her of regular screening. She does appreciate her need for reminders when the screening is due.

The first time they told me I had an abnormal smear, I was only 19 and I had just had my first ...[child]... and I was really scared. I didn't know... said some kind of cells, abnormal cells and they had to be burnt out. So I thought I was going in for like chemotherapy or something when that happened.... But from there I tried to keep up with appointments.... But I have to be reminded; I don't put it off, really. (Aroha, Int. 1)

At her previous medical centre, Louise had been given pamphlets about cervical screening but with no explanations she felt she had never known what it was all about to make it routine self-care. A major barrier to self-care was the trauma she had experienced:

When I came to yous, you pulled out the women's body, the bottom half of the woman's body and the different information in the clear folders and yous talked me through it.... I asked [nurse's name] if I could play some music, and that got me comfortable and relaxed ... the music, the atmosphere had taken ... all the bad experience that I had had growing up, had gone. I was relaxed right through. Normally when I go on the bed and ... it comes to putting my legs up, they tense and they lock ... but that time they didn't.... Because I got taught through the information.... That's top of the list, really, for me anyway, because I've never had that and in three years time I would have another smear, with the same people hopefully (*laughs*). (Int. 2)

Negative past experiences bodily remembered may be barriers to health care engagement. The experience of support and an informative environment produced a sense of the achievement of self-care and an imagining of participating again in a place that was to Louise a healing place.

Previously Pam had understood from the doctor taking her cervical smear that it was good for her health and to keep her safe. She hadn't been given information she understood, not information required for informed consent to the procedure and programme, as practised in a therapeutic landscape:

It was just that it was to keep me safe down there, pretty much.... I knew what it was about but when you explained and pulled out the picture I thought, 'Dam, I've had about four and this is the first time....' So, no, it hadn't been fully explained, and not properly, not how you explained it. 'Oh, true, is that what they're for, is that what they're doing?' Didn't actually know what they were for. I just knew it was better for my health so just went along with it. (Int. 1)

The babies, the growing children, were central to the mothers but there was acknowledgement that the mothers needed to look after themselves, their own health, keep themselves safe in order to care for their children, and for future generations. Having a structure in place for themselves, "a mindset" (Ani, Int. 2), is contingent on having timely information and support:

The right information, the right time, and I think its got to be okay if everybody has got that in place to keep themselves safe as well as their babies, moko, you know. 'Cause it's all about the kids, and making sure you're safe, 'cause if you're not a hundred per cent how are you expected to look after your babies. (Angel, Int. 1)

And its like you need to take care of yourself to take care of your babies and I know I don't. I know I think about them more then [myself], and I should think about myself first. If you can't take care of yourself you can't take care of them. (Shar, Int. 1)

Like people say if you can't look after yourself while you're carrying, then you can't look after your baby. (Patricia, Int. 1)

Ani talks of the role of one generation teaching the young that to survive the dramas that come for everyone in life, they need to be looking after themselves, such as doing preventative checks: "A thing that you're doing to value yourself so that with all this crap happening you're still doing that" (Int. 2). She sees a role for nurses in the community to encourage people; teaching self-care should happen at points of contact in education and health:

It's having a mindset.... Maybe people need to be taught at a young age 'You're going to have dramas in your life and if you want to be able to cope with it better, then you need to be looking after yourself before, during and after'.... And I think its good to have community nurses to sometimes encourage people to do that for themselves.... It has to be instilled like early, throughout the medical process or even at schools, it's really important to... (Ani, Int. 2)

While Dolores acknowledges 'good factors now' in information giving, she voices the fear of unknowingness for young people when engaging with health care including young people not knowing it is their right to know about their own body. Knowledge about her or his rights and about their bodies is for 'everybody':

There's nothing worse than going into the unknown and not knowing, you know so, only there are some good factors, now. But I just feel for those that don't know that they have a right because it's their body, and that's another teaching I suppose for everybody. (Int. 2)

Knowledge is a component of healing places and in an ideal therapeutic landscape the women have networks and connections to culturally safe spaces that are places of healing for them. The places of healing have network systems that are supportive and informational as a right, enabling the women to maintain their self-care for the sake of their own wellbeing, and to maintain intergenerational responsibilities of care.

Remembering and imagining: "For my kids"

Women remembering their own struggles, their experience of difficulty in accessing appropriate information and support for themselves and their children, expressed the hope their children would receive help when they needed it in their futures. They imagined a good life. There was some self-blame:

For them to have a good healthy life, a happy life, and hopefully get all the help and support they need that I didn't get, maybe ... for my kids, yeah (Fran, Int. 2).

Actually seeing the right help at the right time (Angel, Int. 1).

Well, actually being more clever than we are now.... Like going to the right people, doing the right thing, learning... (Patricia, Int. 1).

Ani expresses her vision for the future in terms of changes in the culture of her family to make it more supportive to deal with health issues. When relationships are difficult, “it’s hard to have the energy for other things” (Int. 1). Her vision is for the next generations to be:

Peaceful, violence-free, that would be the main thing.... We’ve got really bad relationships in our family... Openness, and supportiveness, and good communication, and warm-heartedness.... That’s what I’d like most, in seven generations for it to be more peaceful, more harmonious, people to get on better.... What can make a difference health-wise is having those relationships where you are on the up and up, where you’re brought up where there’s a lot of awhi, a lot of love, a real ngāwiri, a real ease of things without everything having to be big dramatic issues... and things go in the too-hard basket, too much drama. There’s a lot of drama in our family. (Ani, Int. 1)

More specifically, when considering her children having babies, Ani would like “to think I could be supportive in general... and make sure there isn’t economic hardship, if I could” (Int.2). Considering her own experience she would like to educate her family about choosing partners as, “what sort of partner to pick has a huge (*emphasised*) bearing about what sort of stresses you’ll be under having a child.” (Int. 2)

Louise is motivated to improve her own wellbeing by her concerns for her children, currently in whānau care:

I want them to have a brighter future than what I had. So I’m trying to change where they don’t see Mum getting hurt all the time, cause that’s not a life for them. Like any parent we want them to have a good future, a good up bringing, which they have gotten, cause I couldn’t at that time. I’m slowly getting there with my babies.... I didn’t want them to go through what Mum was going through, make them suffer for something they didn’t do. (Louise, Int. 1)

Pam’s vision for the future for her children is made in the context of having had her first baby in her mid-teens, a number following, and now being a sole parent living with her mother while waiting for a Housing New Zealand⁴⁷ house sufficient for her size of family. Pam wants them to be able to celebrate their twenty-first birthdays, which for their whānau doesn’t happen if they have already had a baby, and she talks to the older ones about their dreams, dreams that

⁴⁷ Housing New Zealand: Government agency providing social housing (<http://www.hnzc.co.nz>).

could be considered to move them into the mainstream of life in Aotearoa New Zealand:

I just want them to be happy, healthy, safe; to know that they're fully loved and they've got a home to come to and people that love them. The whole whānau, you know, not just one person. Education-wise, I just hope they do really, really well, a lot better than me because I dropped out of school way, way too young after having my son. I hope they all make it to their twenty-firsts, 'Like your uncles (*laughs*), make it to your twenty-firsts; don't be like your Mummy. I had kids before my time. What do you want to do when you grow up? What do you want to be?' And my son goes, 'Oh, I want to be a doctor, Mum, I want to fix people.' 'Aye, my son, oh cool, that's a good dream.' And he goes, 'Oh, hang on, but I want to be a builder, too, so I can build you and Dad a home, Mum.' 'Oh, never mind my son, you've got big dreams, but don't you worry about building us a whare, you build you a whare, first, and I'll come and stay with you.' Then I ask my baby, 'What'a you want to do?' 'I want to be a McDonald's girl.' 'What! No! Why do you want to be a McDonald's...? Oh, maybe you'll own (*emphasised*) one of the McDonald's, aye, my darling? That sounds better.' 'No, Mum, I just want to be a McDonald's girl (*laughing*)'. (Pam, Int. 2)

Patricia wants to teach her own small children early about how to keep safe "The danger that's out there..." (Int. 1). Having experienced the problems in her whānau of alcohol abuse and tobacco being used to solve problems, she wants her children to learn alternative strategies, about situations to avoid, and the reality of peer pressure and social media: "I try to talk to my kids, 'Not going there [pub]'...[and]... No smoking, definitely.... The friends...I think it's the crowd really. Either that or teach them not to be followers.... Face book and stuff" (Int. 1).

Dolores assesses the negative identity dilemma for Māori youth and their parents and imagines a respectful, giving and understanding environment. As an adult in formal education Dolores makes connections between Aotearoa New Zealand's history of colonisation and the ongoing struggles of Māori. Being robbed of history contributes to the struggle, and learning about that history is personally for Dolores both difficult and spiritual.

At the end of the day it's about respecting each other.... our people are still struggling I'm not happy with that.... we've been robbed of our own history.... I'm still learning about my history, that's hard learning that sort of stuff. It's quite spiritual, too.... I have decolonised myself a wee bit, getting better but its for our kids to empower them... like how I was when I was young, 'Oh no, being a Māori is not good'. So we need to change it and say, 'Oh no, being a Māori is great, it's super duper and be proud of who you are'... as we can see the breakdown with our young people is that education's not happening cos why? Cos they're

not being looked after. They're just being shoved in the corner, 'Ok, you're just a problem, we'll leave the problem in the corner and work with the rest'.... So straight away their way of thinking, their spirit, their within and out is crying out for help, but no-one's listening aye, even us as a people. So if our young people are being turfed out to the side, it just makes me wonder, 'What's happening to our parents? Are they feeling the same? Inadequate? ... Maybe it could be because their way of thinking is that, 'Well I'm not clever enough, I can't help my children', but they can. So it's having people in the right places to support anybody really.... It doesn't matter whether it's in the health, or whatever sector, but let's be more understanding and giving to people. (Dolores, Int. 2)

The women saw the landscape for their children lush with possibilities. For the right of their children to reach their potential they need early support to access the broad socioeconomic determinants of health, including appropriate education, to realise their dreams and that of their whānau for them. Attitudes of respect, understanding and giving from health and other sectors contrast with marginalising spaces for Māori youth and their parents in the decolonising project.

Bodies as landscape: "I'd be interested in learning about ... both bodies"

Most of the women remembered their mothers' silences in preparing them for puberty, and their first menstruation distress. Most learnt little about their reproductive bodies from whānau, or antenatal services or other mainstream health care encounters. Most believed it was the responsibility of parents to teach their children about their bodies, and most didn't know how.

Pam hasn't thought about talking about boys' bodies to her daughters, or girls' to sons. She identifies two questions they ask that she finds difficult to answer for their age:

At the moment I don't know how old they should be before I start talking about boys, their bodies, because they ask, 'Mum, how does the baby get born?' I don't know how to answer that sort of question. 'Oh, Mummy and Daddy makes a baby.' 'But how?' And I'm like, 'Oh, when you're older we'll have another kōrero about this, okay?' 'Oh, yes,' and they run off. You know that's the one question about how a baby's born, that always gets me especially for any kid's that so small.... And then, 'Do we come out of the puku?' Or, 'Where does the baby come from?' 'Um, I'll answer that question in another year or two, my darling.' 'Oh, yes.' So those are the two questions I get stuck on.... I just leave it because of how to explain it. (Pam, Int. 2)

Pam would like to learn ways to prepare her children to care for their bodies: "I'm definitely interested in making sure these ones are safe and health-wise" (Int. 2). Shar says for her young daughters, "That's what schools are for (*laughs*), no. I will tell them but what age do you teach

them? I don't know what to do really." An aunty taught her daughter anatomical names from an early age and Shar reflected, "It's a good thing for them to know so if something were to happen to them they'd know someone had touched." She has so far taught her small daughter the word " 'poo-poo' I didn't want to call it the other name ... vagina" (Int. 2).

Patricia initially said she would leave it to the father to teach their son about his body as, "He had to bring up the brother" (Int. 1). Reflecting on the intimate partner violence she has experienced she wanted to be the one to teach their son how to treat women, and she wanted to know about the male body, too. "...I'd rather tell my son the way to treat women. But for his body I'd rather his father...I wouldn't have a clue about a male's body" (Int. 1). If there was a parenting course to support parents to teach their boys and girls about their bodies Patricia says, "I'd be interested in learning about...both bodies (Int. 1). She also thinks if she had known about her own body she wouldn't have had a baby so soon, and Patricia sees it's the parents' responsibility to teach their children. It shouldn't be left to the nans, "They've finished now (*laughing*); they still got the babysitting" (Int. 1). Neither is it the role of the school. "I think it's my role... as a parent, yeah" (Int. 1). Patricia wants her own children to have more information growing up than she had. "Better than what we got...Teaching them more about life than what we knew about life" (Int. 1). Currently Patricia doesn't use the city library, "I don't have a card" (Int. 1) and although she hasn't got her own Internet access, she accesses it through her friend. Patricia would be interested in parenting programmes that support parents, including with resources, how to teach their children about their bodies. "I'd be interested in learning about...both bodies" (Int. 1).

Fran wants her children to learn about their bodies "as early as possible, I reckon" (Int. 2) and uses "penis" with her preschool son and "down there" when referring to the female genital area with her pre-pubescent daughter (Int. 2). Shar wants her fourteen-year-old son to delay having sex and outlines her imagined timetable for him.

The school's already told him about periods and stuff like that. I've just told him, 'Don't have sex, you're too young.' I said to him, 'You've got a whole life-time.' I said, 'This is how it goes: school, work, house, car, woman comes last. When you've got all those in place then you can get you a lady and you'll be settled'. (Int. 2)

Most had not attended mother/daughter puberty classes at school as mothers or daughters. The puberty talks at Makere's school were held in the evening and were for mothers and daughters. Her mother didn't think she needed to go and Makere's dad was going to take her, but she didn't want to go with her dad. Makere thinks that talking about puberty in a school hall is not

a comfortable environment; it's an unsafe space for Māori whānau.

They had a parent's evening, I mean my dad was going to take me but I didn't want to go with dad, everybody else had their mums. You know actually not many Māori ever went to those, because I had some Pākehā friends and they told me that when they went most of the Māori kids in our class didn't go. I think that's how my mum felt. And my mum said, 'Oh, you don't need to go to those. I can tell you.' But actually she didn't. She didn't tell me much at all. She basically just told me how to use... a sanitary belt. (Makere, Int. 1)...When I think about it, it's more the environment. Mum didn't feel comfortable at all going to the school and sitting in the hall and having it talked about like that. It might have been different if there was a one on one opportunity to talk... I know my mum would never have asked questions, either [in the school hall]. (Makere, Int. 2)

Makere went with her own daughter to puberty talks, and a generation later they were still held in a school hall, presented in a similar way, still very few Māori women there and again it wasn't an environment to ask intimate questions, as Makere says: "When I went with [daughter]... out of all the women there, we might only have been two or three Māori... I just thought the way it's presented... you don't get an opportunity to ask sort of intimate questions" (Makere, Int. 2).

In the first interview, Angel acknowledged her responsibility but felt diffident concerning teaching her children about their bodies. She had not been taught about female or male bodies herself. Because of her previous experience of intimate partner violence, and her experience now of a supportive, violence-free relationship, she could confidently educate her children about safe relationships:

I feel it's the parents' responsibility to teach their kids, you know, because I didn't have that knowledge. I'm trying to do the best that I can by my kids. I keep telling my son every day 'It's not nice to hit a woman' (*said softly*). I keep reminding my big girl, 'It's not nice to be hit. That is not nice'.... I've seen my husband, he's broken that violence cycle, you know. He's done that for him as well as making me safe, making our kids safe. In eleven and a half years he has never, never touched me. So I thank the Lord above for giving me someone who doesn't do that to me, as to my ex, every day, every night for nothing. I didn't understand that. But now I've got an understanding of domestic violence and it's not right and it's not okay. I've got that confidence because I've been there, whereas body parts and that, I didn't really know what was going on. (Int. 1)

Angel had thought that as the mother she would prepare her daughters and their father their sons. However, between the two interviews Angel participated in a marae-based, nurse-led education session at Mother's Group on male and female anatomy and sexually transmitted infections. With her new (simple) resources and information from a group setting that was safe and appropriate for her, she was able to educate her husband about male bodies, begin preparing her pre-pubescent daughter, and feels confident to talk with their sons about how their bodies work:

We've done anatomy with young [nurse's name visiting Mother's group]. I learnt a lot (*emphasised*) from her ... the female anatomy to how it all works to a male's anatomy.... the penis and the scrotum... how everything functions into where the sperm is kept and how long the sperm sort of like sits there and ferments.... and it's done where its simple English that we could understand and it's not in doctors' words where its like 20 letters to just mean one thing....

As to before we done this study, you know, I would have just left [husband] to do it all with the boys.... When I have come home with my piece of paper and I'm sharing my information, poor [husband] was like, 'What? Aye? Where's that?' You know then having that information readily for him and actually showing him within the diagram of how his body is inside. And I think he learnt a lot but I think he's still sitting back.... But I feel strong within myself that I could give my boys that information as well as my girls ... now I know where the cervix is and how all that comes into whare tangata for birthing preparation ... and I explain to my big girl about her periods.... just sitting down and talking to her Mummy to girlie, kind of thing. It was great. And I said to her 'If that ever happens at school, just go and tell your teacher and they'd be able to ring Mummy up and we'd be able to come and get you'. And she goes, 'And spoil me, aye, Mum, cause I'd be a lady' (*laughs*). So it's all about this spoiling at the end of that conversation, you know. And I'm glad. And so I'm thankful that I could do that with ease. I didn't really stumble about it. I felt really confident. (Int. 2)

The women did not want to continue the silences of the past about developing bodies, the unspoken geography of sexual and reproductive health. The sacredness of the body (August, 2005; Lovell et al., 2007) needed protecting and the parents had responsibilities. There were gaps in the connections and networks to enable them access to knowledge and resources, to develop confidence to prepare their own children to keep them safe.

Conclusion

The interacting dynamic of spaces and places past and present, physical and cultural, societal and individual impact health and health care engagement. The women remembered back and imagined future therapeutic landscapes of potential. They identified creative possibilities for themselves, for their children's futures, to progress what they themselves did not have for themselves, and in their parenting to promote health and aid access to appropriate health services. Sometimes, the landscape envisioned included their children's children, whānau future, Māori youth and their parents. There was a relationship between learning and having support and healing, the learning and support being at times both spaces and places, and networks and connections in the remembered and imagined therapeutic landscape.

Chapter Eight: Discussion

Mapping the complexity of the influences on the health and health care engagement of 15 urban Māori women as landscapes past, present and future meets the enquiry aim⁴⁸, and is a critical geography of health. The discussion of the findings is framed by Hokowhitu's (2010b) question⁴⁹: "How do Indigenous peoples interpret authenticity... what are the inauthentic identities Indigenous peoples have tethered themselves to in the unsteady waters since colonisation?" (p. 13). This framing is then overlaid with interpretations of critical theory in terms of both positioning and challenging power relations as relevant to these women's stories. A secure identity is a recognised universal human right (Human Rights Commission, 2010; United Nations, 1948, 2008). How the women perceived they were viewed, their difference understood and legitimated, how power was enacted out, affected health care engagement and informs the Kawa Whakaruruhau categories of difference and power for culturally safe nursing care. Study limitations are identified.

Identity: Interpreted authenticities and (in)authenticities

Interpreted authentic identities as Māori women were mostly the traditional interwoven whakapapa connections to whānau, hapū, iwi, to land, language, tikanga. Often simultaneously, there were varying identities to areas of urban place-making where they, and at times the generation before them, had contributed to communities, urban spaces of migration. Some recognised simultaneous Tauīwi identities in their authenticity. (In)authentic identities are argued here to be embodiments of historical trauma⁵⁰, bodily remembered intergenerationally and expressed in this study as 'our lot'. Persisting perceptions of illness that is 'my' disease, risk of illness, and poverty understood as being Māori are argued as (in)authentic identities. The embodiment of the experiences of (in)authentic identity impacts health and health care engagement and are viewed here through the theory of chronicity.

⁴⁸ *Chapter One: Introduction* "In light of the health disparities of Māori women the aim of this research is to explore from the experiences of Māori women in an urban setting, influences on their health and health care engagement in Aotearoa New Zealand."

⁴⁹ *Chapter Three: Mapping the theoretical terrain*

⁵⁰ The violence suffered by Indigenous Peoples in early contacts with Europeans is seen by Indigenous as deep wounding to the spirits and souls that continues and needs healing at individual and structural levels. It is named "transgenerational trauma," and as creating "trauma trails" by Australian Aboriginal, Judy Atkinson (2002, p. 10). Native American healer and Western psychologist, Eduardo Duran (2006), gives several names: "A horrendous holocaust. Systematic genocide.... 'soul wound', intergenerational trauma, or historical trauma" (p. 7). Māori leader, Tariana Turia (2000) has called it a "holocaust," causing "Post Colonial Traumatic Stress Disorder (PCTSD)"(p. 1).

Whakapapa connections: Place and place-making

For some of the women traditional landscapes engendered a sense of wellbeing and authentic identity, which is reflected in the whakatauki of Ngāti Hau of the Whanganui river area, “Ko au te awa, ko te awa ko au (I am the river and the river is me)” (Turia, 2001; Young, 2009). Their firm sense of identity was demonstrated in on-going involvement and contribution to their rural and traditional place and in connecting their children to that place where one day at life’s end the women wished to be buried alongside their tūpuna/tūpuna. As Indigenous women they demonstrate a connection to nature (Johnson & Murton, 2007); they are “...people of place” (Cajete, 1999b, p. 15). There was evidence, too, of women and their whānau place-making in the urban area, putting down roots, creating intergenerational ‘homesteads’ mentally constructing identity within their urban landscape (Gesler & Kearns, 2002). Shared Te Ao Māori spaces, such as urban marae, educational, sport, cultural and religious/spiritual places, positively reflect Kemp’s (2011) view that, “place experiences resonate across the life course, shaping sense of self in the world along with attitudes to the world in general” (p. 11).

Durie (1998, 2001b) contends access to Te Ao Māori, is fundamental for Māori wellbeing. “A secure identity not only includes a sense of being Māori but also the capacity to access both cultural and physical resources, such as Māori land, Māori language, marae, and whānau” (Durie, 1998, p. 197). Further, with a secure identity, better educational and health outcomes are achieved even in the face of socioeconomic adversity. However, the ongoing connection to the land, language and cultural resources of their forebears, to iwi, hapū and even whānau was not the experience of all the women. From her study with youth in South Auckland, Borrell (2005) warns of the risk of further marginalisation for those who do not have access to cultural markers. For all the women in this urban study there was some sense of disruption in different spaces through the processes of colonisation. There was loss of land as a whakapapa and economic base, migration from traditional areas, adoption outside of whānau, hapū and iwi, loss of language and traditions, and mixed ancestry. Disruptions in knowledge of, and access to whakapapa place, appeared to affect for some women both a sense of rootedness and identity, disturbing their wellbeing.

Whakapapa disruptions: Heterogeneity as authenticity

While some stories gave glimpses of deep traditional connections or disruptions, the women acknowledged the “situated fluidity” (Hokowhitu, 2010b, p. 12) of their Māori and Western Settler ancestry⁵¹ in their identity as Indigenous. Or for some women, in-between-ness, as Webber (2008) experiences life, living between Māori and Pākehā worlds and seen by Māori as Pākehā, and by Pākehā as Māori. Sometimes it may have seemed to the women that a Māori

⁵¹ *Chapter Five: Generational Influences and landscape: A whakapapa of health*

and Tauīwi binary was being enacted on them when they or their whānau were othered in health care engagement as Māori, and ancestry common with the health care provider ignored. However, Hokowhitu (2010b) resists locating identity within the Western Settler and Māori binary as in his view that would reinforce structures of power.

A few women told of their whakapapa as Māori women simultaneously with the Pacific ancestry of their children and grandchildren. To Te Punga Somerville (2010) the migratory and Pacific traditions of Māori are not in contradiction with Māori Indigenous traditions of the land, and Māori share the waka traditions with Pacific that "...enables us to notice more and different things (migration, diaspora, Polynesianness, sea-centrism and so on) than if we focus solely on those parts of ourselves that are 'Indigenous' " (pp. 52-53). The women who have Pacific children are positive about their children's heterogeneous identities wanting their children to know their different sides, to know who they are.

In her study of three generations of Māori women Houkamau (2006) found multiple expressions of Māori identity leading her to promote expansion of the traditionally held identity paradigms to incorporate Māori identity heterogeneity. Webber (2008) calls for a third space to be recognised, an authentic bridging space between Māori and Pākehā worlds, a health-giving space. Hokowhitu promotes an imaginative Indigenous space of multiple subjectivities that is beyond "singularity of truth and conclusion" (Hokowhitu, 2010b, p.13). Imaginative spaces may align with the women's Indigenous heterogeneous situatedness as authentic identity. (In)authentic identities will be considered later in this discussion as first the role of language in identity, health and health care engagement are considered with particular emphasis on intergenerational silences about bodies.

Language, identity, and generational knowledges

In a positional paper on multilingual education, UNESCO⁵² (2003) acknowledges the association of language with identity, and the respect of language with peace in communities:

Language is not only a tool for communication and knowledge but also a fundamental attribute of cultural identity and empowerment, both for the individual and the group.

Respect for the languages of persons belonging to different linguistic communities therefore is essential to peaceful cohabitation. (p. 16)

Most participants were not fluent in their mother-tongue⁵³ language even though fluency is a

⁵² United Nations Educational, Scientific and Cultural Organization

basic human right (UNESCO, 2003). A 1953 UNESCO report on New Zealand education concluded that Māori "had lost much that was valuable in his (sic) own culture and had not yet assimilated the European culture" (p. 39). Losing mother tongue language does not equate with success in the foreign language; it is challenging for the learner "to grasp any new concept which is so alien to his (sic) cultural environment that it cannot readily find expression in his (sic) mother tongue" (UNESCO, 1953, p. 47).

The devaluing of language influenced wellbeing by affecting identity construction and by contributing to intergenerational silences⁵⁴. Pihama (2001) names her parents' generation as the "beaten generation" (p. 115), beaten physically, and in every other way challenged to stay alive that may have led to the intergenerational silences. Many of the women referred to the silences of the previous generation in preparing them for menstruation, pregnancy, birthing, and various aspects of mothering knowledges that belong to women's space, traditionally contributing to their accepted mana as women (Yates-Smith, 2006). A contemporary claim is "that the natural mana possessed by women has been robbed by colonisation, by the way history has been defined and by the impact of social and economic change on Maori women" (L.T. Smith, Hohepa, & Maori Education Research and Development Unit, University of Auckland, 1990, p. 17).

Different participants remembered thinking they were dying when as young girls they began menstruating, of having babies through lack of body knowledge, of unknowingness in birthing and about postnatal feelings, and generational interruptions in knowing how to breastfeed. Losing mother tongue language diminishes ability to pass on knowledge inherent in the culture to succeeding generations and diminishes ability to incorporate new information and to contribute to global knowledge. As one African linguist writes:

Mother tongue education has psychological and educational advantages.... a foreign language ...diminishes and retards the development of the intellectual potential of the African child, will take its toll on the ability of African economies to develop and the ability of Africans to make original contributions to knowledge. (Chumbow, 2005, p. 190)

The women also described challenges in accessing body knowledge from both educational and health services. The barriers included universal services that excluded, such as mother-daughter

⁵³ 'Mother tongue' is defined by UNESCO (1953) as the language through which, "... every human being first learns to formulate and express his (sic) ideas about himself (sic) and about the world in which he (sic) lives." (p. 47)

⁵⁴ *Chapter Five: Generational Influences and landscape: A whakapapa of health*

evenings for puberty education in impersonal education facilities, antenatal educational services and parenting programmes, and health consultations that didn't inform adequately before procedures, all of which are discussed later in the chapter. Suffice at this point to acknowledge that more equitable health and education services engagement may have ensued, if Aotearoa New Zealand had a rich history of cross-pollination between Māori and Tauiwi knowledges and worldviews about women's bodies. The women told stories of current resistances by Māori women to the losses of intergenerational women's knowledges, as does the literature (Murphy, 2013). Murphy (2013) reclaims Māori menstrual knowledges from stories inherent in pre-colonial oral traditional literatures that contribute to women's whakapapa as mana wāhine, reclaimings to also inform health and educational services.

The women expressed their authentic identity as Māori women in whakapapa to traditional place, language, even dialect of that geography, and to the customs of their whānau. Authentic identity is also expressed as being a Māori woman and valuing the language but not knowing it, and of not knowing the details of traditional geography or even whānau. Authentic identity, experienced existentially as difference and contradiction and fluidity (Hokowhitu, 2010b), may be expressed in place-making in the urban area, in wanting for themselves and their children to know, sometimes when circumstances have settled, that even through intergenerational disruptions and dislocations they are Māori, proudly Māori. Now for a return to a consideration of (in)authentic identities presented as chronicities of risk, inhabiting disease, and poverty that I argue jeopardise health and health care engagement.

(In)authentic identities of chronicity

The women's stories often disclosed ongoing fear of diagnosis of an illness, or its complications where illness is perceived as inevitable, 'in the family', 'in the genes', and the word 'cancer' for many families, is conceived as being synonymous with death. Stories told were frequently gendered, for example, care of whānau with illness, the perceived risk of developing illnesses such as breast and cervical cancers, and the conditions of their living in poverty. Some saw illness as avoidable through life-style choices and being checked early. The higher prevalence of illness and premature mortality for Māori increased women's burdens, similar to Indigenous communities globally (Baker et al., 2013; Ward, Jowsey, Haora, Aspin, & Yen, 2011) leading to ethnicity being seen as a risk factor (Leal Ferreira & Chesley Lang, 2006).

In reflecting on global Indigenous facticity, on intergenerational illness and associated perceptions, the theory of chronicity provided illumination. It connected with theories of bodily remembering (E. Cartwright, 2007; Casey, 2000) and cultural memories (Rodríguez & Fortier, 2007) as in *Chapter Three: Mapping the theoretical terrain*. There are, however, two

theoretical strands to differentiate. The first strand promotes enduring conditions as ‘genetically’ determined (McDermott, 1998; Neel, 1962, 1982, 1999; Poudrier, 2007), and I include, but don’t discuss, the life course explanation here which highlights the potential importance of the foetal environment in relation to certain genetic conditions (Räisänen, Bekkers, Boddington, Sarangi, & Clarke, 2006). The second strand concerns that contribution to chronicity of historical, political, racial and socioeconomic forces and stressors of civilisation (House et al., 1982; Meleis, 2011; Salmón, 1999; Wiedman, 2010). As Krieger (2005) points out, “embodiment... is literal” (p. 350). Our bodies in fact tell the stories of our lives, stories known and unknown. We are “simultaneously social beings and biological organisms” (Krieger, 2005, p. 350).

Prior to the differentiation of diabetes one and two, Neel (1962, 1982, 1999) hypothesised the existence of a thrifty gene in early human development. It was purported that the thrifty gene enabled hunters and gatherers to store food in their bodies from times of abundance for times of famine. In modern times with a constant abundance of food and without famine the thrifty gene predisposes to diabetes. The thrifty gene hypothesis lingers in the popular and professional psyche (Sydney Morning Herald, 2010) despite being discredited in Neel’s own lifetime (Everett, 2011; Leal Ferreira & Chesley Lang, 2006; McDermott, 1998; Speakman & Westerterp, 2013).

Neel (1982) owned the physiological failure of the original hypothesis but maintained the “principle” still stood (p. 284), believing a physiological, rather than environmental solution requiring self-discipline would be found (Neel, 1999). There is a moral implication here in blaming the individual, for example, for eating energy dense foods. Questioning both the ethics and science of aligning “genetics” with “race,” McDermott (1998, p. 11189) notes the influence the thrifty gene concept has had on funding for research and treatment perpetuating individualistic and fatalistic attitudes among health professionals and affected communities. The thrifty gene hypothesis contributes to the social determinants of health as aetiology of disease being ignored (Paradies et al., 2007).

Leal Ferreira and Chesley Lang (2006) consider the diversity globally of Indigenous Peoples and pose a key question: “How can a genetic cause be applied across the borders to 300 million people divided into thousands of ethnic groups, living across the planet under strikingly different circumstances?” (p. 12). Researcher knowledge of Indigenous communities’ trade routes is an Indigenous example questioning the validity of homogeneity in genetic studies, which in doing so, contributes to the decolonisation of science literature (Poudrier, 2007). Critics of Neel’s hypothesis have named it as “biological determinism” (McDermott, 1998, p.

1190), “genetic determinism [and]... scientific racism” (Leal Ferreira & Chesley Lang, 2006, p. 14). The popular notion of genetic determinism may have influenced women in this study in their references to genetic inheritance by both encouraging and discouraging women’s engagement with health services as seen in this study and in the literature (Kahui Tautoko Consulting Ltd, 2007). A few of the women interviewed had through education begun to understand the broader social determinants of health, and in particular the effects of colonisation on their wellbeing.

The second theoretical strand of chronicity has its roots in medical anthropology significantly articulated by Estroff (1981, 1993) in her life-course view of people suffering with schizophrenia (Weaver & Mendenhall, 2014). Estroff (1993) defined chronicity as: “... the persistence in time of limitations and suffering *and* to the resulting disabilities as they are socially and culturally defined and lived” (p. 250, author’s emphasis). Within the definition are the factors of time, biology, relationships, perceptions, and the broader determinants of health that are pertinent to the women’s stories. Within broader determinants of health are Indigenous histories of ongoing colonisation. The theory of chronicity as the interplay of biology with the persistence and limitations of suffering over time as experienced and lived out within particular social and cultural contexts has been applied in different contexts. In this study I employ chronicity broadly to include from the findings risk of enduring illness, inhabiting disease, and poverty, as each are potentially limiting, persistent over time, cause suffering, illness, and (dis)ability. Chronicities of risk encompass structural chronicities, modernity/civilisation, and chronicities of stress and of everyday life. Chronicities are argued as (in)authentic identities reflecting the embodiment of historical trauma, the interwoven whakapapa of land, language and health (Mikaere, 2011) impacting the health and health care engagement of the participants.

Chronicity of risk: An (in)authentic identity

Manderson and Smith-Morris (2010) use the term, “chronicity of risk” (p. 15) for both structural and individual experiences of enduring conditions, and the “chronicity of everyday life” (p. 11) for the political and socioeconomic determinants of health that contribute to suffering.

Enduring structural factors, termed “structural chronicities” by Wiedman (2012, p. 596), create the conditions for exposure to illness, and ongoing structural inequalities hinder access to cure or to manage well the illness. A chronicity of risk is associated with perceptions (Manderson & Smith-Morris, 2010). In considering individual experiences of enduring conditions, a chronicity of risk foregrounds the multiple complexity of chronicity more broadly than a stigmatised individual biomedical category. Pertinent to this enquiry, Wiedman (2010, 2012) links historical trauma to the enduring conditions disproportionately affecting Indigenous Peoples. The linking to historical trauma may be clarified through the theories of bodily remembering (E.

Cartwright, 2007; Casey, 2000) and cultural memories (Rodríguez & Fortier, 2007), which may be the mechanisms of the embodiment of the whakapapa of land, language and health (Mikaere, 2011). Bodily remembering, cultural memories, unknown but felt stories are argued as being synonymous with intergenerational embodiment of the loss of land, language and health expressed in this study as “our lot” (Makere, Int. 2). The fear of risk of diagnosis being “our lot” linked across the generations with vulnerability, with struggle, and with being Māori.

Before considering other pertinent chronicities in the literature, I'll briefly mention the ‘time’ aspect of chronicity. The women’s unspoken question in a chronicity of risk is ‘when’. When will the intergenerational whānau illness or complication strike? Manderson and Smith Morris (2010) argue that time in illness in Western societies is generally categorised as acute or chronic, with an emphasis on individual symptoms of illness at the expense of “social, economic, political, or biological...” aetiology (p. 31). The invisibility of inequities in political and socioeconomic structures that determine access to treatment and life-long management contrasts with the visibility of an acute episode, and recovery or an early death. Categorisation of illness and time as acute and chronic is no longer clearly defined (Manderson & Smith-Morris, 2010). Acute conditions, such as HIV infection, cancers, or injuries that were previously time-limited to recovery or death, may be managed with the ongoing risk of reoccurrence or deterioration. Reoccurrence or deterioration is dependent on often structurally and politically invisible (to the powerful) socioeconomic structures, for example, the accessibility of welcoming and appropriate health services in the women’s stories. There may be other health, well-being and quality of life implications as these once acute conditions move into the area of becoming chronic conditions necessitating other approaches to health service provision and policy. I return to linking other chronicities in the literature with the women’s stories.

Chronicity for some women was living with the risks across generations that come from alcohol and other drug abuse, risks of whānau suicide and early deaths; an intergenerational chronicity of risk of loss or death. Constantly living in the flight or fight mode physiologically intended for intermittent periods for survival leads to what Wiedman (2010) terms “chronicities of stress” (p. 50). The “...emotional suffering from adverse, traumatic stresses” (p. 50) more highly represented in populations with historical trauma and socioeconomic adversities is seen as an important contributing factor, for example, to metabolic syndrome. The mechanisms and pathways by which such a chronicity of stress may act to contribute to, in this case, metabolic syndrome are complex and the construct of ‘embodiment’ has served to provide some very good work in this area. For example, examination of the relationship between the experience of discrimination and risk of high blood pressure (as a contributor to the development of diabetes) in black compared to white Americans (Krieger & Sydney, 1996; Krieger, 2000; Williams,

Neighbors & Jackson, 2003). Similarly relevant to the women's stories, there is possible evidence of a potential contribution to breast cancer of accumulative DNA damage from chronic psychological stresses (Flint & Bovbjerg, 2012; Gehlert, Mininger, & Cipriano-Steffens, 2011; McClintock, Conzen, Gehlert, Masi, & Olopade, 2005).

The disruptions for Indigenous Peoples in loss of whakapapa land, language, knowledges and access to cultural resources are interrelated phenomena with what Weidman (2010) has called the "chronicities of modernity" (p. 38) such as obesity, diabetes and metabolic syndrome⁵⁵, and Prior (1971) "the price of civilization" (p. 2), adding gout to the above examples. Cajete (1999b) includes "existential problems, such as high rates of alcoholism, suicide, abuse of self and others, depression, and other social and spiritual ills" (p. 17). These effects are argued as being the result of the disruption of traditional life grounded in physical labour and subsistence living (Cajete, 1999b; Price, 1939; Prior, 1971; Wiedman, 2010). Bio diverse and spiritually based ecological knowledge has been lost as traditional ways associated with identity (Cajete, 1999a) have been replaced by cash economies, time- convenient foods based on white flour, sugar, salt, saturated fats, and more sedentary ways of living. Indigenous Peoples, often within a generation, have experienced the development of the chronicities of civilisation at rates faster than the peoples who displaced them (Wiedman, 2012). The foregrounding of the contribution to chronicity of civilisation illuminates the effects of the dominance and hegemony in whiteness theory on the health and health care engagement of Indigenous Peoples. In the next section I discuss the language of illness and embodied experiences of inhabiting disease as (in)authentic identity.

Chronicity and inhabiting disease: An (in)authentic identity

Estroff (1981, 1993) looked at the language of illness and how symbolic and sociocultural processes transform self and identity in chronic conditions "by the linguistic joining of identity with diagnosis" (Estroff, 1993, p. 256). In particular, Estroff compared 'I am' (for example, diabetic) and 'I have' (for example, appendicitis) and suggested that the linguistic use of 'I am' denotes an inhabiting and enduring disease, while 'I have' indicates an illness episode of short duration. 'I am' illnesses are more likely to have the stigma of individual moral failure, (alcoholic, schizophrenic) which could be argued holds for type two diabetes. The use of 'I am' diabetic, epileptic, asthmatic does have the linguistic sense of the disease being my identity, when I see the inhabiting illness as being 'me'. Similarly, to say someone is diabetic, epileptic, rather than has or suffers from a named illness, risks locating their authentic identities within

⁵⁵ Metabolic Syndrome (MetS) comprises at least three risk factors for illnesses such as diabetes, heart disease and stroke (National Heart Blood and Lung Institute, 2011). Risk factors include high blood pressure, high fasting blood glucose, high triglycerides, low HDL cholesterol, and abdominal obesity.

stigmatised disease (Smith-Morris, 2010). For the women in this study this risks their authenticity as mana wāhine.

Smith-Morris (2010) speaks to fluctuating illness experiences over the life span, where self-perceived identity of having an illness shifts to inhabiting illness; the disrupting and restabilising of identity: “Life is a series of disruptions, small or large, to which we eventually either adjust or succumb. Therefore, identity is constantly in flux” (p. 25). Authentic identity in this view of chronicity is the experience of "...balance, multiple states of health, or health as successful coping" (p. 36). Risks to achieving balance and successful coping for Indigenous women may be the significant disruptions in the provision of support, care and other resources for themselves or for whānau, and the experiences of caring for whānau with illness in previous generations. An outdated understanding of the course and prognosis of that illness, which now may potentially be different, may influence health care engagement, early diagnoses, and effective treatment.

The nursing of Māori women within the cultural safety mantle of Kawa Whakaruruhau recognises the essence of mana wāhine with the centrality of the roles of women within Māori society and beyond. It also recognises the affects on women's mana of the historical and ongoing effects of colonisation. Māori women experiencing fluctuating periods of health may be supported by the development or adaptation of tools such as the medication self-management tool (Bailey et al., 2013)⁵⁶. Incorporated into the tool would be assessment by whānau of concordant, culturally safe relationships with their health care team. Simultaneously, the health care team would assess with whānau areas of support needed to enable women and their whānau to achieve balance and successful coping in an enabling society (Chouinard, Hall, & Wilton, 2010). The literature and this study support Indigenous, public health and community-based initiatives, such as the Mana Wahine programme, as empowering and strengthening of authentic identity with values congruent between the women and provider as in Hauora Kaupapa Māori⁵⁷ (Wenn, 2007, p. 206). Structural causes of illness are further discussed below. A World Health Organisation report on diabetes concludes that while the potential for prevention, earlier diagnosis and management of diabetes has changed over the generations with global and national development of the understanding of disease processes, it is the structural improvements in health care that still reflect inequities (Whiting, Unwin, & Roglic, 2010).

⁵⁶ See *Chapter Two: Literature Review*

⁵⁷ See *Chapter One: Introduction*

Chronicity of poverty: Place and (in)authentic identity

Srinivasin and Croyle (2011) contend that place matters and women and their whānau in this study were positively or negatively linked to environments urban and traditional that impacted their health and health care engagement. For some women and their families living in poverty, in communities of poverty, the persistent and limiting nature of being poor in a low socioeconomic area with high risks to well being, is argued as being a chronicity of poverty and as such (in)authentic identity. The accretion over their lifetimes of “structural inequalities” may well influence the control women have to make healthy choices for themselves and their whānau (Weaver & Mendenhall, 2014, p. 101). Environments impact health such as healthy housing, distance to procuring healthy food, exercise, schools, health services, communities and recreational settings (Srinivasan & Croyle, 2011). Similarly, distances to spiritual environments of meaning, for those whose connections and access to such places remain intact, including for example, whānau land, marae and urupā. Conversely, women’s health is affected by immediacy of place to fast foods, liquor outlets, and unsafe communities, impoverished or absent or distant amenities. Each of these environments in a community network contributes an interlocking effect on the health of women and their families; in effect, place matters (Srinivasan & Croyle, 2011).

The contribution of society’s structures, such as urban housing and transport policies, to the chronicity of poverty and persistent lower gradients of health violates human rights (United Nations, 1966/1976). An Aotearoa New Zealand study found that living in a same ethnicity-dense area is protective from racial discrimination but that such benefits may be hidden where there is poverty (Bécares et al., 2013). From an ethnography of shantytown inhabitants in the Brazilian Northeast, Scheper-Hughes (1992) termed the societal and administrative indifference to the normalising of poverty in certain populations as “everyday violence” (for example, p. 4). Explaining this some years later Scheper-Hughes (2006) says:

... as violence and disease are linked in more ordinary way in social and bureaucratic indifference toward the excess morbidity and mortality of certain populations under the assumption that alarming statistics are not to be seen as alarming at all but rather as 'normal' to the population and therefore to be 'expected.' Another, is in the rush to biologize and racialize gross differences with respect to vulnerability to disease. Thus, alcoholism, depression, and suicide, obesity and diabetes in Indigenous communities have been normalized and racilized, consciously or not, in etiological theories. (p. xviii)

Poverty impacted the health of the women who, at the time of the study, had significant material disadvantage highlighting the causal pathways between relative deprivation and health outcome (Graham, MacLeod, Dibben, & Johnston, 2004). As told by some women, material disadvantage

effects were attending the free emergency department rather than a fee-paying medical centre. Or suffering while on a waiting list for publicly provided surgery as they couldn't afford private health insurance, and in their mind, more immediate care, more choice. There was changing medical centres because of cost and a money attitude from a service in which they did not feel heard, supported or informed and endeavouring to have more concerns addressed in an appointment time for themselves and their family than the medical centre would allow. Transport to access the health service and filling medical prescriptions were at times problematic for some women.

A material disadvantage effect may be the need to access the doctor at all. For example, if the women had dry, insulated homes and low cost heating, they and their children may not have suffered from the repeat respiratory illnesses that had led them to repeatedly seek medical services. Or if when they had accessed the medical centre the context of the illness had been identified and social disadvantage addressed, for example in housing, repeat visits may have been unnecessary. A multi-country respiratory study on children shows the adverse effects of damp housing on both wheeze occurrence and severity likely through non-atopic mechanisms such as the damp housing (Weinmayr et al., 2013). The poverty of rental housing poorly maintained, house crowding and homelessness, are structural and political issues contributing to psychosocial stresses and those with the greatest material disadvantage generally have the poorest health (Hill, 2008). The inequitable and compounding stresses for women living in poverty are obvious. Living in inadequate housing, accessing appropriate, affordable, and quality health care, providing other necessities of life for themselves and their families, is further compounded by increased exposure to environmental hazards (Meleis, 2011; Mwangangi, 2011). For some of the women in the study exposure to the environmental hazards of poverty increased exposure to varying forms of sexual, physical, emotional and intimate partner violence. Most of the women did not have the resources to influence public space, for example, they did not have civic influence on the provision of amenities or transport for easy access to various facilities.

Urbanisation and access to waged employment can improve women's health and engagement with health services through greater independence economically and socially (Meleis, 2011; Obrist et al., 2007). Overall, the best health is enjoyed by those who have the power in society afforded by "...good educational achievement, secure jobs, adequate income, comfortable housing" (Hill, 2008, p. 33); secure work provides access to contacts, skills and resources. It was at work in Māori health and education that some of the women interviewed received formal and informal support to access health care for themselves. Employment may have negative effects when it is low paid, insecure, and difficult to access transport-wise. Other issues are poor work conditions and precarious childcare when taking time off work is problematic. In accessing health care some of the women said they put their children's wellbeing before their own, prioritising financial, time and energy resources for the children. Managing and

negotiating various systems may increase women's vulnerability to hazards, stresses, and burdens of care, affecting their health and health care engagement; the impact of chronic poverty experienced everyday.

Power structures in society are basic to discussions of chronicities of poverty and are manifested in inequality between groups as social gradients of health, which are difficult to dismantle (Hayes, 2004). Māori/Tauīwi disparities are seen as being based on racism with the on-going power structures rooted in colonisation (Robson, 2008). While there is now wide socioeconomic diversity amongst Māori (C. Cunningham, 2008) the chronicity of poverty in Aotearoa is disproportionately experienced by Māori women and their whānau (Perry, 2013). As Matheson and Dew (2008) conclude: "People are not poor because they are sick; they are sick because they are poor" (p. 13). It is an (in)authentic identity. Some recognise that to address health inequalities and improve the overall health of a nation those suffering the poorest health must be broadly targeted (Graham, Boyle, Curtis, & Moore, 2004). At the same time structural factors leading to and perpetuating inequalities in health outcomes between ethnic groups must be seen as a priority (Commission on Social Determinants of Health, 2008). There was evidence of connections to equitable services to address socioeconomic disparities of health both being made and not being made for the women by health services. Most of the women's stories are reflected in reports for the government to address poverty broadly, such as improving housing, to alleviate the burden of inequities in health and its broader determinants (Children's Commissioner's Expert Advisory Group on Solutions to Child Poverty, 2012; Howden-Chapman, Bierre, & Cunningham, 2013). Given that communities subjected to poverty mostly carry the burden of disease, and in the absence of a causal mechanism of disease, McDermott (1998) promotes public health interventions as ethical that are "community based and designed" (p. 1193).

In this section I have argued that chronicities of inhabiting disease, risk of disease, and poverty are (in)authentic identities that impact health and health care engagement for Māori women and their whānau. Aetiology of disease as genetic determinism is (in)authentic identity and burdensome; understanding the effects of the processes of historical trauma and broader socioeconomic determinants empowers (Leal Ferreira & Chesley Lang, 2006). Cultural safety education and practice requires nurses to critique historical and socioeconomic structures that impact health and health care engagement, differentiating authentic identities when nursing alongside, for and with Māori at individual, service and structural levels. The theory of chronicity contributes by focusing away from an individual biomedical approach towards informed, culturally safe and concordant nursing partnerships that are enabling. Such partnerships address the various access barriers to health care engagement that Māori women

encounter.

Power relations and spatiality

Power relations in various health spaces affected the health and health care engagement of the women both positively and negatively. Limited knowledge about health, health care and processes were evidence of the limited power some of the women had. Their stories of dissatisfaction often reflected a health care provider emphasis on individual biology that ignored structural and contextual causes of ill health, failing to assess and address the total environment of the woman, or to provide adequate education and support. Few felt able to complain directly to the health professional about their service, on occasion that was effective. Only one woman in this study gave evidence of taking the necessary steps to progress her concerns beyond the health professional giving the service and that was with the support of a Māori health provider.

In the *Maternity Consumer Survey 2011*, which used survey and qualitative comment on maternity services, Māori and Pacific women's response rate was less than half that of NZ European women limiting Māori and Pacific input into appropriate change (Ministry of Health, 2012b). Other fora for providing comment on maternity services could have been considered by the Ministry such as focus group hui and fono, which may have resulted in higher response rates from Māori and Pacific women. In this current study, most of the women did not know how, or lacked support, to make a complaint beyond the health professional to influence provider, process or structural change, such as to management, or to the *Health and Disability Service* (Health & Disability Commissioner, 2009a; 2009b). The result was some women's stories reflected an (in)authentic identity assigned to them by health care services similar to racially based stereotypes (McCreanor & Nairn, 2002).

The frequent absence of nurses in health care stories the women told may reflect powerful interests in health care provision. At other times it could mean nurses were doing the everyday fundamentals competently and caringly in an unnoticed way. It may also have been that I am a nurse and participants may not always have felt entirely comfortable sharing stories that reflected unfavourably on nurses. The women did relate accessing nursing services in marae, medical/health centres, mental health services, telehealth, well child and other community services; in-patient, emergency, and outpatient hospital services; hospice and elderly care facilities. As most participants were mothers, midwifery services discussed were both community and hospital based and covered engagement from first contact to postnatal discharge. While locum medical services and not being able to see their preferred doctor was on occasions experienced as distressing, a different doctor at times provided the service the women valued. Gender of health professional was a criterion in provider selection. However, a health

professional was valued regardless of gender if the health professional was interested in the woman or her whānau member, listened, knew or accessed the medical history and whānau background, assessed thoroughly and provided appropriate interventions, helpful explanations and information throughout the intervention process and for future management.

Medical discourses that displace the recipient/s of health care, women and their families, from the apex of the hierarchical health care triangle (F. Richardson, 2010) may serve to also displace other health workers. In primary health when the women were most dissatisfied by the service they received from their medical centre there occurred an invisibility of a team approach. Even when, for example, the prime reason for the visit was clearly within a primary health care nurse scope of practice. There is a dominating discourse that primary health is associated with seeing the doctor and the cost of seeing the doctor was a stated reason for whānau not attending health care. The doctor not listening, judging, rushing, assessing inadequately, being rough, not giving any or inadequate information about prescribed medication, not referring to other community or health care workers and agencies, was associated with women's expressed dissatisfaction, frustration, anger. This may reflect a general practitioner's incorrect understanding, as in McCreanor and Nairn (2002), that current Māori health status is "a function of being Maori" (p. 5); Māori stereotypically constructed in general practice as not taking responsibility for their own health and health care. While it is possible that the nurses and other team members at the medical centres where dissatisfaction was expressed with particular doctor/s may have practised differently to the general practitioner/s, it cannot be assumed.

A Californian study found training community health workers to deliver tailored follow-up from a hospital clinic of women with abnormal Pap smears a successful strategy (Engelstad et al., 2005). In low resource countries community health workers are valued for working at the family and community level, addressing social issues, giving low-level health advice, making connections to primary care facilities, and feeding back social and community data (M. Harris, 2013). A British study to improve breast screening rates trained medical centre receptionists and found those with the same culture and language as the women achieved best improvement in uptake of breast screening (Atri et al., 1997). An Aotearoa New Zealand rural medical centre worked together and with the predominantly Māori community to successfully improve breast screening rates (Thomson, Crengle, & Lawrenson, 2009).

Nurses in this study would have been equipped and potentially available in the services, as narrated in the particular stories expressing dissatisfaction with the general practitioner, for health assessments, smear-taking and assessing sexual and reproductive health; for providing immunisations; for giving information and education on a variety of family health matters such

as skin infestations and infections, and for collaboratively with the whānau and health team establishing and managing ongoing complex health care plans including referral to other agencies, for example, for home assessment, heating and insulation. Literature on integrated services within the Aotearoa New Zealand PHO environment, and international primary health care literature, notes various roles in the health care team⁵⁸.

Gesler and Kearns (2002) argue that biomedical ideologies stress biological causes, classifications of disease, and the medical expert at the expense of other determinants of health (see p. 47 above). Hegemonic practice by the expert compounded by intersecting differences based on ethnicity, gender and class (P. Jackson, 1989) may have been experienced in the stories of lack of health professional interest in health and whānau history, social situation, or in providing adequate assessments or information, such as about medications. Silence, not giving information, speaking in ways with words the women couldn't understand reveal "the politics of language.... reflecting and reinforcing social boundaries in space and time" (P. Jackson, 1989, p. 169).

Seemingly unacknowledged use of professional power may have impacted the women's or their whānau health and health care engagement. The development of Māori health providers and organisations such as Mana Wahine, Tu Kotahi Māori Asthma⁵⁹, and the National Kaitiaki Group in the National Cervical Screening Unit⁶⁰, provide spaces and places where Māori understandings of wellness are foundational (Wenn, 2007). The struggle for social inclusion by Māori, is seen by L. T. Smith (2006) as an ongoing struggle at different levels for authenticity of identity, "to be Māori as defined by Māori in New Zealand" (p. 249).

While a number of the women's stories told of exclusions there were other stories of inclusion in mainstream services and through targeted programmes as in 'by Māori for Māori' services, venues of welcome, appropriate assessment of needs inclusive of the circumstances of the woman and her whānau. Services that were respectful, thorough and appropriate were services that made efforts to understand difference, and paralleled efforts to empower to meet needs, services experienced as under Kawa Whakaruruhau.

⁵⁸ *Chapter Two: Literature Review*

⁵⁹ *Chapter One: Introduction*

⁶⁰ Introduced in *Chapter One: Introduction* - The National Kaitiaki Group established by law in 1995 is to protect Māori values ascribed to Te Whare Tangata and Māori women's information, and to ensure Māori women's information is only used to advantage Māori women (National Screening Unit, n.d.).

Kawa Whakaruruhau: Cultural safety in Māori health

Cultural safety, Kawa Whakaruruhau, in institutions of health care provision and in health professional practice, is about power and difference, which in this work concerns Māori health, and Māori as recipients of care. Difference is broadly defined and power is a contested force. Foucault's (1994) view on both the neutrality and hazard capability of power has been discussed previously⁶¹. Cultural values, beliefs, and practices structure both the women's experiences of health, and health care providers' provision of services (Gesler & Kearns, 2002). Institutions of power in society across sectors, such as health, education, social services, housing, and employment, impact at the macro, political and systemic level of health care politics and at the micro and individual level of the experiences of health. Within health care providers there are competing influences of power that impact on health care recipients' subjective experience of culturally safe care. At the micro and individual level in hospital settings, Richardson and MacGibbon (2010) found the practice of individual nurses and cultural safety is affected by the vying discourses of "traditional nursing, maintaining an environment of control, and the primacy of medical knowledge"(p. 56).

The serious effects from the conscious or unconscious misuse of health professional and institutional power jeopardised the life chances of women and their whānau through geographies of exclusion (Sibley, 1995), excluding those presenting as different and as challenging (Chouinard et al., 2010; Sibley, 1995). Sibley (1995) argues that, "exclusions take place routinely without most people noticing, which is a particularly important aspect of the problem" (p. xiv) and calls for identification of "forms of socio-spatial exclusion as they are experienced and articulated by the subject groups" (p. x).

Systemic exclusions from health care programmes or services occur, for example, where the universal provision of puberty and antenatal education excludes from programme or service conception Māori participation, Māori values and beliefs; where the programme or service is provided in a venue or manner that excludes Māori women's involvement through cultural discomfort or practical access barriers. A health care service or programme excludes where the advertised promotion fails to connect as relevant to the felt needs of women under-represented in the health care it is promoting. Or where the service or programme is unwelcoming and not accompanied by personal health professional invitation with encouragement and assistance. Or where there is no open invitation for a support person or Māori whānau to attend together. Knowledge and power are acknowledged inter-related phenomena (Foucault, 1994; Freire,

⁶¹ Foucault's (1994) view on power is discussed in *Chapter Four: Mapping the Theoretical Terrain*.

1994) consciously or unconsciously exercised, and associated here with information management and resource distribution (Ramsden, 2002).

Unawareness of difference to self when planning and providing health programmes and services is obliviousness to the inherent power of the privileged self over those who experience themselves differently through class, socioeconomic and health status, through gender, sexuality, ethnicity (O'Grady, 2005). On being a different skin colour O'Grady (2005) writes:

The overwhelming ways in which being white is taken for granted and continually affirmed in western cultures renders many white people blind to the fact of having a skin colour at all, let alone to the reality that its social privileging requires the derogation of differently coloured skin. Those constantly subjected to the discriminating 'gaze' of white culture are denied the luxury of such colour blindness. (p. 19)

Obliviousness to our discriminating gaze calls for reflective practice, the practising of reflexivity (Barnard, 1990) to see the effects of our collective whiteness in its various forms reflected back to us in the lives and conditions of those from whom our skin colour differs. Or the differences of other intersecting binaries, such as teen Māori mother, beneficiary, early school leaver, living in a crowded and unhealthy rental; 'other' to the privilege of those providing health care and programmes.

There is a caution here, as the establishment of a programme for a particular group may serve to exclude by objectifying the group that is the focus of the intervention, for example, by treating all Māori as the same and the binary of Tauwi self. To Foucault (1994), a subject is objectivised when he/she is "...either divided inside himself (sic) or divided from others.... Examples are the mad and the sane, the sick and the healthy, the criminals and the 'good boys'(sic)"(p. 326). While Foucault's examples here, and his general work, may be critiqued for excluding gender and ethnicity binaries (O'Grady, 2005), an appraisal by Pihama (2001) of the pedagogy of schools for Māori girls serves as an illustration in Aotearoa New Zealand's colonial history of the objectivising of Māori women and the disempowering results.

Pihama (2001) argues that Settler men in the colonial government consciously enacted the binaries of race, gender, colonisation, and class at legislative and curriculum levels. By preparing Māori girls only for subservient domestic roles in society, they were precluded from leadership roles within both Pākehā and Māori social orders. Objectivising marginalises and makes subservient the needs of the 'object' to the wants of the discriminating and powerful gaze.

The dangerous use of power upheld by patronising and injurious attitudes at macro level potentially impacts health through non-engagement with health services and programmes of the target group due to the group's lack of confidence in what is provided or the seeming irrelevance of programmes or services. Non-engagement may be primarily as a result of exclusion from input or discussion into the development of such programmes and services, which frequently do not reflect the realities of those for whom the service is 'allegedly' provided.

A United Kingdom study investigating health promotion adaptations for people comprising ethnic minorities synthesised "conventional ethnicity⁶² ... [and] contextual ethnicity" (Liu et al., 2012, p. 118). Contextual ethnicity is "the lived dimensions of ethnicity, these including dynamic relationships with particular spaces and places, intergroup heterogeneity and previous experience with other health interventions that impacted on how new adapted health interventions were received" (p. 97). While the study wasn't about organic Indigenous programmes and networks, an understanding of contextual ethnicity may be useful at the Taiwi Māori interface at all levels of health care planning and provision in focusing, for example, on particular age groups, geographical areas, or Māori in a particular socioeconomic quintile, or with an identified health challenge.

As in the study, adapting health promotion programmes involving the target group cognisant of their lived reality, may mitigate against health programmes and health care using stereotypical and immutable concepts at the macro level that objectivise and treat all Māori as the same. The Liu et al. (2012) study included the objectives that the target group was involved from conception to dissemination, and the health promotion programme was sustainable. Evaluation by the target group to ascertain appropriateness and effectiveness is inherent in sustainability. Māori know when they receive a good service, soon-to-be-practising registered nurses were assured by Matieu Rei, Māori leader in health care provision in a 2012 speech at a local polytechnic to BN (Māori)⁶³ graduands. Being subject to medical interventions and health programmes without the opportunity to be heard and to hear, is culturally unsafe.

⁶² 'Ethnicity' in Liu et al.'s (2012) study includes one or more: "ancestry, culture, language, physical features and religion " (p. 4). Religion and spirituality are used alternatively by Liu et al.'s study.

⁶³ Matiu Rei, Executive Director of Te Runanga o Toa Rangatira, was a key speaker at the inaugural Bachelor of Nursing (Māori) graduation at Whitireia Polytechnic, Porirua, September 29th, 2012. A group from KMHSS attended in support of a graduating RN colleague.

(In)authentic identities exist where individual and collective worth as Māori reflects the negative Tauīwi Māori binary of colonisation, the othering of Māori. Othering is a category in whiteness theory and the women who resisted attending a particular medical centre ever again, endangering their own health status, described the negative attitudes of othering towards them from health professionals in that service as contributing to their resistance. Where there was a welcome, an understanding of the woman's circumstances, the legitimisation of difference, the experience of being listened to and the provision of appropriate information, linkages and support in assessment, intervention and post-intervention management, the care was experienced as safe. Authentic identities are experienced as legitimated in culturally safe care and the discussion in the final section centres on participants' hopes for themselves and their whānau and on what was working for them as Māori women.

Authentic identity: Remembering and imagining

Remembering is argued in this thesis as encompassing both consciously remembered events, and the women's bodily remembered historical trauma of their tīpuna/tūpuna, their own particular whānau history about which, through the processes of colonisation knowledge may be denied. The women bodily remembered stories both with and without words (Grace, 1998). Imagining embodies the women's hopes and dreams for themselves and their whānau for the now and for the generations to come. Some of the women had come to mostly understand their stories against the historical, political, cultural and socioeconomic landscape. They contended that Māori needed to know why things are as they are in Aotearoa New Zealand and that being Māori is not second class or putting up with 'our lot' of colonisation. Being Māori is to be proud; it is authentic identity.

Women remembered services they had received as spaces and places of healing, or as fissures in the landscape affecting subsequent health care engagement. Some saw the connections or disconnections more on an individual basis rather than reflecting a structural fissure, for example, the women who wanted their children to be smarter than what they had been in accessing services (Patricia, Int. 1; Angel, Int. 1). Most women did not articulate their disconnections in their health care engagement as the outcome of experiencing, for example, racism in those health services. The women who blamed themselves enacted an effect of hegemonic racism, and racism is a determinant of health (R. B. Harris et al., 2013). The women who expressed an implicit self-view as a second class citizen, their self-blame and attaching of (in)authentic identity, is seeing themselves in relation to Tauīwi in unequal power relationships (Fine & Weis, 2008). Addressing the broader structural inequities of colonisation under Kawa Whakaruruhau/cultural safety includes the right of Māori women to be at the centre of services that include Māori in order to address inequities.

Authentic identity and health care services

Health care that enabled the women's engagement provided education that the women experienced as respectful, empowering, and as meeting their requirements as Māori women, and/or that of their whānau. National advertising for breast and cervical screening centring Māori and Pacific women informed women and their families, their work colleagues and friendship groups, and with support contributed to engagement with screening services. Bethune and Lewis (2009) also found social marketing encouraged conversations about cervical screening leading to changes in health behaviours for Māori, Pacific and other under-represented women.

There were stories in which the women recognised their right to know about their own bodies and the proposed assessments and interventions; to be heard, to be informed properly about services and the ability to access support if needed. Information is more than just being given a pamphlet at the health care provider or in the mail. The women appreciated illustrated information about their bodies with face-to-face explanations. Wanting support in secondary and tertiary health care from Māori support staff suggests an expressed need to feel safe by being with someone perceived as being the same as themselves, but with the power of being an insider to the system. Integrated Māori support services across primary, secondary and tertiary health care are indicated.

Ramsden (2002) reminds, however, that women and their whānau need to experience Kawa Whakaruruhau/cultural safety in 'by Māori for Māori' services, too. Considering the heterogeneity of Māori, it cannot be assumed. Being a Māori support worker, nurse or other health professional does not necessarily equate with sameness with a Māori woman in terms of experiences of gender, sexuality, socioeconomic position, iwi, beliefs, age, access to cultural resources or other forms of potential difference. But in 'by Māori for Māori' services there is potentially significant understanding for Kawa Whakaruruhau and the provision of culturally safe care.

The women in this study covered a childbearing age span of about forty years. Most had never attended, been invited to attend, or known about, or understood the relevance of antenatal programmes, which reflects a serious failing on the part of our health system and services. Given the higher fertility rate, the youthful population structure, and higher rates of adverse birth outcomes and SUDI⁶⁴, antenatal care is one aspect of inequitable maternal and child care which should be urgently addressed in partnership with Māori (Barnes et al., 2013; Ratima & Crengle, 2012; Smylie et al., 2010). Māori maternity service consumers were more dissatisfied

⁶⁴ SUDI: Sudden unexplained death of an infant

with maternity services than other respondents (Ministry of Health, 2012b). Women want services that are culturally responsive and holistic (Lyford & Cook, 2005; Ratima & Crengle, 2012; Wilson, 2003). Further research is needed to understand the barriers to antenatal participation for young Māori women, including structural and funding barriers, and research to plan relevant and targeted heterogeneous programmes cognisant of contextual ethnicity (Liu et al., 2012) and life course (Barnes et al., 2013; Bucharski et al., 1999; Ratima & Crengle, 2012).

Authentic identity: Mana Wahine

Most women related how education by Māori women for Māori women, as in the Mana Wahine programme, encouraged screening and other health care engagement. In the Mana Wahine programme, information is given in group settings alongside other Māori women, in individual consultations, or at health promotion events at various venues such as cultural festivals. Screening services and support along the screening pathway are provided, including the navigating of treatment services if required. Māori determination to improve the 'lot' of Māori women's health status resists othering, and in empowering Māori women, is subversive. The initiatives by Māori communities in health, and the leadership exercised by Māori women, puts pressure on mainstream services challenging appropriateness, affordability and accessibility. Passing on knowledges from Māori women's worldview demonstrates the mana of women (L. T. Smith et al., 1990). The Mana Wahine programme is a model for other categories of health education and support.

Some women had experienced preparing members of their family, sisters, children, or friends, to manage menstruation or to give birth. They mostly expressed a lack of confidence in knowing what and how to talk about bodies, or where to access information and support. In the women's stories there was little said about menopause apart from various health concerns surfacing in midlife. In my practice as a marae-based nurse and smear taker within the Mana Wahine programme, the same lack of information, support and confidence about body knowledge exists. Midlife and older women navigate the sometimes-stormy passage of menopause without bringing their concerns to their medical centre, and if attending for other issues, are never asked about their sexual and reproductive health or asked in a way that the woman feels safe to respond. This is a major and important area, which needs to be addressed.

Authentic identity: Supported and informed to parent

A few of the women had participated in a targeted marae-based mothers' group to which they and their small children had been respectfully transported. They credited the mothers' group as being a safe place, where they had gained insight into their experiences as women, and as mothers. The women appreciated the opportunities for friendship, peer reflection and support, access to social services and for Māori cultural expression, and where they had increased their

knowledge about bodies, health and wellbeing. The mothers' group programme enabled their visions for themselves and their whānau to expand, visions including that their children would have access to appropriate information and support earlier than they themselves had. The by Māori for Māori mothers' group begins with the women's felt need and the world the women understand, the space they inhabit. It provides an enabling environment to achieve what they want for themselves and their whānau.

The women in the study remembered their own life experiences and imagined support available for parents to deal with their issues, and to receive support and information with parenting, such as learning how to teach their young ones self-care at home from an early age and through their school years. They wanted their children to be given information and support when they engaged with health care so that they would develop a mindset that operated protectively through disruptive events in the continuum of life. Most of the women wanted to feel confident and know they had up-to-date information when talking with both their daughters and their sons about their bodies, teaching them how to treat each other, being safe in intimate relationships, knowing why, what/who, how and when to access services. They wanted to teach children about the influences of peer and social media pressures, and give them strategies to deal with issues, for them to have alternatives to alcohol and other drug abuse. The women wanted for their children environments that are supportive, communicative, and informative, for their children to keep going with education, to have dreams and to reach them. In their remembering and imaging the women describe a landscape where there is political will to enable equitable meeting of social determinants of health⁶⁵ (Marmot, Friel, Bell, Houweling, & Taylor, 2008). The women's remembering and imagining supports contextual ethnicity (Liu et al., 2012) and life course approaches (Barnes et al., 2013; Bucharski et al., 1999; Ratima & Crengle, 2012) approaches.

Spaces and services that are culturally appropriate for Māori women and their whānau and for their age and stage are experienced as safe places to talk about bodies, to learn about safety in intimacy. Such spaces and services are not found in large, impersonal places such as school halls. Schools at all levels could partner with marae for joint Māori and school initiatives in spaces conducive to being Māori, so whānau are involved in curriculum development and delivery. Marae services could be equipped to develop and maintain resources for whānau to

⁶⁵*The Commission on Social Determinants of Health* was sponsored by the World Health Organization to gather evidence for a global movement to address inequity in health within and between nations (Commission on Social Determinants of Health, 2008). Inequity exists where differences in health between Peoples could be assessed and addressed broadly and holistically by reasonable action to improve living conditions and the inequitable sharing of resources.

access across all media, for all age groups, such as marae-based web-based services, and libraries of relevant up-to-date resources for local parents to use with their own whānau. Marae-based educators, such as the nurse in Angel's story (p. 156) speaking to the Mother's group, are well positioned to prepare parents/caregivers individually and in groups, for example, resourcing them with a take-home visual and relevant written material that could link to a marae-based web site. Knowledge is related to power (Foucault, 1994; Freire, 1994) and I argue from this study that women who are grounded in the knowledge of what mana wāhine means are informed, current, relevant and resourced to teach and, in turn, to empower their whānau of all ages.

Limitations

Māori women are heterogeneous and this qualitative study undertaken from a Pākehā researcher's nursing position in an urban Māori health provider could not hope to cover that heterogeneity. The urban Māori participants all had roots in rural traditional areas. Their experiences and those of their different whānau, hapū and iwi have commonalities, for example, in on-going processes of colonisation, and they have differences in the detail of those processes and in their understanding of them. As an effect of colonisation there were wide differences in connections to, and knowledge about their traditional roots, their whakapapa. The research may be different with rural marae-based Māori women still in their traditional area, or with urban or rural Māori women recruited from a non-Māori or mainstream research site. It may be different with takatāpui or women older than mid-fifty or younger than twenty.

Further limitations may be that I was working at the research site as a registered nurse and I conducted all the interviews, a Pākehā woman nursing clinician. The reason most said they had responded to the invitation to be a participant in this research was because they knew me and wanted to assist me in my learning; they would not have participated in the study with a stranger. The women were very generous with their stories, their taonga both personal and whānau, and for that I am very grateful. It was notable that no one criticised any of the staff or the work of our service, Kokiri Marae Health and Social Services. It may be a limitation that none disaffected by our service participated, either because it was marae-based or because it was research that I was undertaking.

Conclusions

Hokowhitu's (2010b) questions on Indigenous People's interpretation of authentic and (in)authentic identities since the advent of colonisation frames the discussion on the influences on the health and health care engagement of urban Māori women. The women interpreted authenticity in whakapapa to iwi, hapū, whānau, and to traditional geography, language and customs. Authenticity was also expressed as place-making in the urban area, recognising

disruptions under colonisation. (In)authentic identities are argued as embodied chronicities of inhabiting disease, risk of illness, and poverty. Conscious and unconscious intergenerational bodily remembering and cultural memories of historical trauma may be mechanisms for the embodiment of chronicity. (In)authentic identities are experienced in the body as barriers to health and health care engagement. Places and spaces are not experienced as power-neutral, and the theory of Kawa Whakaruruhau/cultural safety in nursing, enables those spaces and places to be experienced as healing for Māori women and their whānau. Authentic identity is experienced when the women remember then experience empowerment through knowledge and support and imagine with hope an equitable future for themselves and their whānau. For as Freire (1994) intuitively, "I do not understand human existence, and the struggle to improve it, apart from hope and dream. Hope is an ontological need" (p. 64). The liberty to dream with hope is based on knowledge and empowerment: an authentic identity. The next chapter concludes the study and offers recommendations for research, theory and practice.

Chapter Nine: Conclusion

My pre-question awareness of disparities for Māori was informed by “spots of time” from my early years (Blaiklock, 1981, p. 73; Wordsworth, 1799/1987, p. 25), the deaths of midlife women in the same whānau known to me as ‘aunties’. Life and career experiences contributed to an increased awareness becoming an inner imperative in my nursing practice at Kokiri Marae Health and Social Services. At the macro level national policy based on Te Tiriti o Waitangi had been developed to address access, appropriateness and affordability of health care for Māori. At the everyday and micro level of nursing in an urban marae community, I was aware of, and at times constrained by, perplexing disparities experienced by Māori women and their whānau in accessing appropriate and affordable services. I was also aware of a hegemonic discourse that, mostly covertly, blamed Māori for the condition of their lives. As part of a critical nursing practice reflection the research aim became: *In light of the health disparities of Māori women the aim of this research is to explore from the experiences of Māori women in an urban setting, influences on their health and health care engagement in Aotearoa New Zealand.*

Literature reviewed covered the association of health care engagement with health outcomes, terms used to describe health engagement, and influences on health and health care engagement. The association of health care engagement with health outcomes globally and locally, demonstrates differences in health status between and within countries in the selected literature of maternal health, non-communicable diseases of cancer, and co/multi conditions. Undergirding the literature is health as a human right (United Nations, 1948, 1966/1976), and specifically for this study, an Indigenous right (United Nations, 2008). In maternal health, integrated, life course focused, culturally appropriate health care is recommended in the literature with research on best practice to address the existing health and socioeconomic status of Māori maternity (Barnes et al., 2013; Ratima & Crengle, 2012). Literature linking the provision of screening and treatment services for cancer to women’s health, suggests disparities for Māori women’s access to appropriate health care remains, which has implications for specific and equitable initiatives. Other non-communicable conditions are associated with inequalities in prevention, early diagnosis and treatment. While amenable mortality has declined overall, Māori rates are inequitable (Ministry of Health, 2014a). Some literature reviewed the contested nature of the planning and implementation at different levels of interventions for recipients of care with co/multi conditions.

In extensive literature on health care engagement, the terms ‘compliance’, ‘adherence’ and ‘concordance’ are frequently used, often confusingly, interchangeably, and reflecting different health professional roles. The compliant patient is passive and does what the doctor says. The

adherent patient has come to have more involvement in decision-making about their care and persists with treatment over time. The receiver of health care is often portrayed negatively as non-compliant, non-adherent. The literature is frequently medication-focused. There are exceptions such as holism (McKinnon, 2013) and life style and environmental factors (Cohen, 2009) in nursing literature, and in the WHO literature (Sabaté, 2003). While compliance and adherence describe behaviours, concordance is about relationship, the relationship between the receiver of health care and the health professional provider. Within a concordant relationship, compliance or adherence may or may not be achieved at any given time (McKinnon, 2013). It is the health provider's responsibility to maintain a concordant relationship. To my knowledge concordance and cultural safety have not previously been linked in the literature.

The third section reviews literature that explores various factors broadly influencing health and health care engagement. Critically, literature is reviewed on the influences on Indigenous women of ethnicity, a determinant of health and often experienced with socioeconomic disparity. The influence of racism on health and health care engagement has three aspects: health professional attitudes and behaviours (such as stereotyping), health systems and structures (institutional racism), and effects on individuals of experiencing racism in society (such as perceived prejudice) (Shavers et al., 2012). An effect of experiencing racial prejudice may be internalised racism. Racism is seen in disparities such as Māori health status and ethnicity counting, however, identifying and tracking racism in health care is problematic. Māori as board directors (Panoho, 2012) and as nurses (Huria et al., 2014) in the public health system report the experience of racism in various guises. While Māori are heterogeneous, wide ranging disparities contributing to Māori socioeconomic status are a form of racism as a racial hierarchy maintains disparate structures in society.

The complexity of the nursing praxis issue has been demonstrated within this thesis through the use of qualitative methodology, unstructured interview method, and a critical theory approach. Ethics approval was granted from the Central Regional Ethics Committee of the Health Research Council. Qualitative methodology allowed the complexities of the context of Māori women, their health and health care engagement and that of their whānau to be explored in ways that were culturally appropriate, such as in hui, in an unstructured interview method. The voiced experiences of 15 heterogeneous, urban Māori women, aged from twenty to mid-fifties, provided rich data. The interviews were recorded with consent, transcribed and returned to the women for verification. Most women had a second interview at which beginning themes were clarified. The data were mind mapped to identify codes and themes. Engagement with the literature, and with my supervisors, and ongoing dialogue with marae-based colleagues about everyday practice issues assisted analysis.

Overlapping critical theories have enabled the complexities and hidden power relationships in the women's stories to be viewed cognisant of the women's political, historical, socioeconomic, racial/ethnic/Indigenous, gender, and cultural landscapes. The influences have been presented in this thesis as a critical geography, an interconnecting whakapapa of health, where landscapes, places and spaces, networks and connections are both physical and metaphorical. Landscapes to the reflective viewer tell of the past, the whakapapa of land, language and health (Mikaere, 2011), that connect and disrupt landscapes present, generational influences and historical trauma, the women's own embodied experiences. Places and spaces in landscapes present are experienced in the everyday as places to be at home, as sense of place, as environments sustaining health, or not. Between places and spaces there are networks and connections that network and connect or not, white (and not-so-white) landscapes of power relations and spatiality, geographies of inclusion or exclusion impacting the health and health care engagement of Māori women and their whānau. Reflecting on landscapes enables times past, to meld with places and spaces, networks and connections of landscapes present. The women then remember and imagine a therapeutic landscape. Other critical theories contribute to the geography of health.

Kawa Whakaruruhau/cultural safety theory is a critical theory for nurses and Māori health (Ramsden, 2002). It has categories of power and difference and subjective assessment for critical nursing reflection in clinical and management practice, education and research. Kawa Whakaruruhau/cultural safety informs the theoretical foundation, process, and analysis of the study, and provides a mantle for the participants and their whānau, the marae and marae whānau (colleagues, management, Trust and participating whānau). Conversely, I am protected as the Pākehā nurse clinician/researcher, as well as my sponsoring university. I am aware that my responsibility continues in articles and presentations from this work, and in my future 'ways of being'. I can never walk away, nor would I want to. Other theories, too, have informed understandings of the categories of power and difference discussed in this work.

Whiteness theory provides a framework to critique the power and privilege in the racial hierarchy held by those of us who are white and not-so-white (Fine et al., 2004). In addition, the work of Indigenous scholars who critique gender, race, colonialism/s and identity informing the heterogeneous situated-ness of Indigenous women has also been used to inform this thesis (Mikaere, 2011; Pihama, 2001; L. T. Smith, 1999/2005; Te Punga Somerville, 2010). Theories on bodily remembering (Casey, 2000) and cultural memories (Rodríguez & Fortier, 2007) connect with understandings of intergenerational influences from historical trauma and intergenerational family illnesses and in turn with dimensions of time, biology, suffering,

perceptions, relationships pertinent to chronicity theory (Estroff, 1993). Chronicity in the everyday conditions of life may be experienced as an embodied chronicity of risk (Manderson & Smith-Morris, 2010) and as (in)authentic identity (Hokowhitu, 2010b).

The findings are presented as generational influences on the women's experiences of health and health care engagement; the influences of spaces, places, networks and connections on their health and health care engagement; and as the women remembering and imagining therapeutic landscapes of potential. The women's stories at times showed the interwoven whakapapa of land, language and health, the embodiment of historical trauma, loss of land, language and health, expressed as 'our lot'. Influences from generations past who did what they could to survive the losses of land and language, economic base and knowledges, contributed to the women's health decision-making. There was attachment to place, traditional geography of identity, whakapapa of whānau, hapū, iwi, waka, and to whenua, maunga and awa or moana. For others, there was disruption in whakapapa knowledge and identity making, and there was mixed heritage. Urban place-making, contributing to urban neighbourhoods and communities in urban places enabled connection for most to the urban area and contributed to identity making. Although all the women valued Te Reo highly, few knew it fluently. Devaluing of their language through the processes of colonisation and assimilation may have contributed to loss of knowledges traditionally handed down. In particular, the women encountered silences about their growing bodies, having babies or avoiding pregnancies. Most learnt about the hygiene of menstruation after it started, and some about Māori protocol. Most were welcomed into womanhood.

Most women related knowing of or caring for someone in the whānau with illnesses associated with fear, risk, vulnerability, and inevitability. Individual responses meant some not wanting to know, and others 'being checked', perhaps reflecting access to appropriate health care, knowledge and support. Caring for family members could give an outdated knowledge of illness, prognosis, and complications with advances in understandings of prevention, early diagnosis and treatment. Developing an illness may be embodiment of illness, an inhabiting 'my' condition (Estroff, 1981, 1993) again reflecting life-long access to, and appropriateness of health care. Chronicity theory (Estroff, 1981, 1993; Manderson & Smith-Morris, 2010; Wiedman, 2010, 2012) and the women's framing of illness as risk, as inevitable, in the family, in the genes, and 'our lot' implying 'our lot as Māori women' linked with theories of identity (Hokowhitu, 2010b). I argue that embodiment of a chronicity of the risk of illness, a chronicity of the complications of inhabiting disease, and a chronicity of poverty are (in)authentic identities. (In)authentic identities are experienced in bodies as oppressive and influenced women's health and health care engagement.

The influences on the women's health and health care engagement of space, place, networks and connections were as contested landscapes that could powerfully include or exclude. Geography of space and place is also reflected in the body in geography and the geography of the body. In the first theme, professional-centric services could exclude from place and space those who are disempowered in society by socioeconomic circumstances and poverty, by lack of health provider choice, and possibly ethnicity. A medication-focused health space that powerfully fails to make networks and connections to address socioeconomic and environmental stresses of poverty, contrasts with care and networks and connections for support and information and appropriate home-based services. Systemic exclusions from place and space may be in the framing of programmes, for example, universal antenatal education by health educators and funders. Differing needs of Māori women appear assumed rather than given central place, and not attending may be the Māori woman's self-care against experiencing racialised othering. Time has special relationship with place, when giving time engenders the sense of a listening encounter, of being not judged, of thoroughness in assessment, diagnosis, treatment plan, with healing team-connections to address broader determinants of health. Contested spaces and places that powerfully exclude may be experienced as difficult to access from the women's socioeconomic place, as time-challenged, gendered, racialised, rough, as spaces without negotiation. Constantly revolving staff affects the building and maintenance of trusting and therapeutic relationships.

Body as geography experiences may be insensitive, disrespectful, hierarchical, concerned only for the physical medical event and the giving of pills. In contrast, body as geography experiences may be welcoming, relational, respectful, gentle, giving the woman privacy and ownership of her own body and the space to be able to have a say, giving explanations before and with procedures, always providing follow up with results, explaining medications and side-effects. Geography of body influences spaces and places women attend for their health, while gender of the health professional influences, or is able to be rationalised to enable health care engagement. Some women do prefer service and gender choice. Geography of the body links to all forms of violence, the gendered nature of abusive space. The gendered and racialised nature of poverty increases women's exposure to various forms of violence affecting for years, health and health care engagement. Multidisciplinary, community-based and marae approaches were experienced as culturally safe and healing.

The women remember and from their experiences they imagine what they wanted for themselves and their whānau, and at times for successive generations in landscapes future, therapeutic landscapes of potential. Where they had been othered they imagine being centre to

the service. Remembering difficult health provider encounters, in a therapeutic landscape, the women's agency to seek resolutions to inappropriate health care is supported. In a therapeutic environment, self-care is a mindset and knowledge is important, such as knowing their rights about their own bodies, and attending to self-care before whānau-care so they may care for their whānau. The women imagine a good life for their kids recognising children need early support to access appropriate education and in other ways traverse the gaps in the social determinants of health. The women didn't want to continue the silences of the past, unspoken geography of sexual and reproductive health. They imagine networks and connections needed to access knowledge and resources, to prepare their children for the good life and to keep them safe. Most hadn't attended mother/daughter evenings at school. School halls are an unsafe place for intimate gendered body talk for Māori women. Neither had antenatal services or other mainstream services contributed to their body knowledge.

The women identified creative possibilities for whānau, for their children's futures, to progress what they themselves did not have for themselves, and in their parenting to aid health and to access appropriate health care. The women told in their stories of health care enablement on an interactive, interpersonal level with health professionals. Their experience of concordant and culturally safe relationships at the micro and individual level is affected by the macro, political and structural levels of health care politics and policy, and by the culture of different health care providers. Within that health care culture are the attitudes, behaviours, and self-awareness of power and difference of those employed to provide health care and health programmes. Practices that the women experienced as being safe were wide ranging and often at a practical level, some of which are reflected in the recommendations to follow.

The women's stories contribute to historical, social, economic, political, cultural, and gender understandings in the categories of difference and power in Kawa Whakaruruhau/cultural safety theory for nurses. The women subjectively assessed barriers and enablers for health care engagement. As such this study contributes to the social justice agenda of nursing. As nurses we have both the opportunity and the responsibility to establish culturally safe and concordant relationships with Māori women who are recipients of our nursing care, and to enable Māori women to experience Kawa Whakaruruhau. In a whakapapa of health, landscapes tell of the past, of places and spaces, networks and connections in landscapes present, and therapeutic landscapes of potential are for now and landscapes future.

Chapter Ten: Recommendations

1. Research: Self-reflection tool

Kawa Whakaruruhau as a cultural safety nursing theory for Māori health addresses the categories of difference and power. It involves self-reflection by the nurse and assessment of cultural safety by the receiver of nursing care or user of services and programs. A recommendation is for the development of a self-reflection tool for nurses. Existing literature would be reviewed, any identified tool evaluated, and modified or developed for nurses to self-identify attitudes to difference, and the origin of the influences on those attitudes, to inform self-knowledge. The origin of the influences may include historical events in the nurse's family, class, social, racial, and economic understandings, peers, or media. The tool would include a guide for the nurse to develop their own plan to address self-identified attitudes to difference, which may include discussion with a supervisor in cultural supervision. The role of an appropriately prepared Tauwiwi registered nurse to provide a safe environment for Tauwiwi nursing students or registered nurses to discuss cultural safety and Te Tiriti issues in cultural supervision is linked to the literature (Huria et al., 2014).

2. Research: Culturally appropriate health literacy assessment tool for Māori women

Further research is needed to link the social and historical forces felt and experienced by Māori women inter-generationally with their health decision-making for themselves and their whānau and ways they're supported to address those forces. This may include the development of a culturally appropriate health literacy assessment tool to enable the targeting of resource interventions and support to meet a woman's understanding of health risk and disease inevitability for herself and her whānau. It would be strength based and cognisant of the visions women have for themselves and their whānau.

3. Identified whānau mapping and support intervention

The development under the Whānau Ora Provider initiative of a formalised mapping system for identifying whānau with specific illness histories to assess whānau health literacy and to comprehensively provide:

- Appropriate information and support for whānau over the life span to prevent the development of both chronic conditions and cancer and negate notions of inevitability. This includes support for whānau after the deaths of loved ones.
- Regular screening for early detection.
- Supportive quality of life management for those suffering illness and their whānau.

A mapping system could be developed from primary health organisation enduring illness data, or whānau identified from general practice health history consultation records.

4. Culturally safe, self-medication tool for whānau and health team

Modify, develop and implement a model such as the medication self-management tool (Bailey et al., 2013) to incorporate assessment by:

- whānau of concordant, culturally safe relationships with their health team;
- the health team to assess areas for whānau support to enable self-management of medication.

The integrated health professional team may comprise medical consultants, general practitioner or other prescribers, hospital or community pharmacists, nurses in tertiary, secondary, or primary and community health care, community health workers, and the team may be located within and across providers. The tool will be to assist and empower whānau suffering with enduring illness to achieve optimal wellness.

5. Research: Antenatal preparation for Māori women and their whānau

Given the disparities in birth outcome and SUDI that Māori women and their whānau experience, and given that most of the women who were mothers had not accessed antenatal programmes, community development-based research (Bucharski et al., 1999) is recommended:

- To understand the structural, funding, programme, community and individual whānau barriers to antenatal preparation for Māori women and their whānau.
- To plan relevant and targeted holistic programmes for Māori women and their whānau cognisant of their life course (Barnes et al., 2013; Bucharski et al., 1999; Ratima & Crengle, 2012) and contextual ethnicity (Liu et al., 2012), and their hopes for the future.

6. Strengthening health literacy for Māori women

This study highlights the practical importance of information provision and whānau and health professional relationships; something that Kokiri Marae Health and Social Services (KMHSS) was founded upon and continues to do well. KMHSS is positioned as a conduit of health information, a provider of services and as a culturally appropriate and relational bridge between whānau and other health and social services. All staff that support women across different programmes need to have good health literacy and know culturally appropriate resources available. In an acknowledgement of a constantly evolving knowledge base, the auditing and

collating is recommended of all resources used by KMHSS for women's health broadly, and all information resources available to women who are Māori. This includes web sites for staff and for whānau; presentation material and models; information resources such as booklets, pamphlets, books, CDs, DVDs; knowledge of other appropriate health and social services for Māori women.

7. Supporting Māori parents

Three different strategies are recommended for development under the Whānau Ora Provider's initiative to support parents in the education of their own children about their bodies from an early age and at different stages, with personal assistance, events, and resources. The strategies could be in collaboration with current sexual and reproductive health, parenting, whānau ora, Well Women, nutrition and physical activity, and Tū Kotahi Māori Asthma contracts of a marae-based programme.

1. A library of resources could be developed to cover the developmental stages from growing as preschoolers through middle childhood, pre-puberty, puberty, rangatahi and sexual and reproductive health, to the preparing for parenthood, and keeping healthy bodies' stages across the life span of human development. Book, booklet and DVD resources could be sourced with an emphasis on Māori language and themes to be used as a library service or for purchase.
2. Parenting evenings could be held annually for different developmental stages to encourage parents to talk with accurate information and relevant resources about growing bodies.
3. An annual marae-based parenting show with interactive modeling to engage whānau to talk about growing health-literate tamariki, whānau developing skills to evaluate health information and to make healthy decisions from a Māori perspective from an early age.

Glossary

- Aotearoa** - land of the long white cloud
- Ariki** - chief of chiefs, noble, first born
- Atua** - spiritual being, ancestor whose influence lives on, way of perceiving the world, power over a certain sphere
- Awa** - river
- Awhi** - to embrace, to cherish
- Fono** - any type or size of meeting between people (Pacific)
- Hā** - breath, essence
- Haka** - traditional dance with chants used in war and in peace
- Hapū** - state of being pregnant, conceive; a large section of an iwi comprising whānau with common ancestry
- Hauora** - healthy, fit and well
- Hawaiki** - mythical ancestral land from which Māori migrated to Aotearoa
- Hinengaro** - mind, thought, intellect, conscience, psychological
- Hui** - gathering, meeting, conference.
- Iwi** - extended people group comprising whānau and hapū descended from a common ancestor (whānau→hapū→iwi), nation, nationality; bone, strength
- Kai** - food
- Kaikaranga** - the usually senior woman who performs the ceremonial role of calling visitors on to the marae or other important area, or who is equivalent in the visitors' group responding
- Kai moana** - seafood
- Kāinga** - home, village
- Kaitiaki** - guard, manager
- Kanohi ki te kanohi** - face to face
- Karakia** - prayer
- Karanga** - ceremonial call of welcome or equivalent response from visitors' group
- Kaumātua** - elder
- Kaupapa** - strategy
- Kawa** - formal Māori protocol, as in **Kawa Whakaruruhau**
- Koha** - gift, contribution
- Kōkiri - to advance
- Kōhanga** - nest, **Te Kōhanga Reo** - Māori language nest for preschoolers
- Kura** - school, **Te Kura Kaupapa Māori** - Māori-medium school for primary and/or secondary students

Kōrero - to speak, to discuss, conversation, discussion

Koro/Koroua/Pōua - dialectical differences for grandfather, older man –as used by participating women

Korowai - Cloak, usually made from feathers

Kuia/Taua - dialectical differences for grandmother, older woman-as used by participating women

Mana - integrity, prestige, status

Mana Wahine/Wāhine - inherent prestige, status, of woman/women

Manaakitanga - care for, process of showing respect, kindness, hospitality

Manuhiri - visitor

Māori - Indigenous Peoples of Aotearoa, ordinary

Marae - whānau, hapū, or iwi meeting area incorporating buildings, courtyard and other spaces

Mātauranga Māori - Māori knowledge

Maunga - mountain

Mihi - greeting, tribute

Moana - lake, sea

Mokopuna - grandchild, young generation, **moko** – shortened version (‘mokos’ - Anglicised plural)

Ngāwiri - good-natured

Oranga - health, welfare, livelihood

Pākehā - non-Māori, New Zealander of European or Caucasian descent

Papatūānuku - earth mother in union with the sky father, Rangi-nui

Pāua – abalone (‘pāuas’ - Anglicised plural)

Pito - umbilical cord nearest baby’s abdomen that detaches in the days after birth

Puku - abdomen

Rangatira - high rank, esteemed, chief, chiefly

Rangi-nui - sky father, partner of Papatūānuku, earth mother

Takatāpui - same sex intimate partner/friend, Māori who identify with non-heterosexual orientations

Tāne - man, husband, male partner

Tangi - to weep, to mourn, funeral rites

Tangihanga - mourning, funeral rites, weeping

Taonga - treasure

Tauīwi - foreign people, non-Māori, immigrants

Taurekareka - captured slaves

Tautoko - support

Te Ao Māori - The Māori World usually comprising, Te Reo, Tikanga and Marae

Te Reo - Māori language, dialect

Te Tiriti o Waitangi (1840) - Māori version of The Treaty of Waitangi (1840)

Tikanga - procedure, custom, understanding, reasoning, plan, correct way of relating, behaving, doing

Tinana - body, physical reality of a person

Tipuna/Tupuna - dialectical differences for grandparent, ancestor (**Tīpuna/Tūpuna** - plural)

Tohunga - priestly experts

Tūmatauenga – atua, spiritual being, god over man and war

Tūrangawaewae - a place of right to stand

Tū tangata - to stand tall

Tūtūa - commoner

Urupā - burial place, cemetery

Wahine - woman, wife (**Wāhine** - plural)

Waiata - sing, song, chant

Waimanawa - Hui Waimanawa - *Chapter One: Introduction* – streams of deep emotion from the inner being

Wairua - spirit, soul

Waka - canoe, sometimes used for vehicle. Identity and kin connections to historic migratory canoes

Ware - commoner

Whakawhanaungatanga - process of making connections, of relating to one another

Whakapapa - genealogy, cultural identity, family tree

Whakaruruhau - to protect, shield

Whānau - to be born, to give birth, delivery; extended family; extended family, a people group with a common interest, not necessarily kin, for example, a work whānau

Whanaungatanga - kin responsibility, reciprocity, close relationship

Whangai - a customary practice of adoption or fostering, often grandparents nurturing the first child

Whare - house

Wharenuī - ancestral meetinghouse

Whare tangata - womb

Whenua - ground, country, afterbirth, placenta

Appendix

1. Ethics Approval 2008
2. Ethics Approval 2010 (changes on upgrade to doctoral studies)
3. Information Panui
4. Interviewing Guidelines
5. Participant Consent Panui
6. Transcriber's Confidentiality Agreement



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone: (04) 496 2405
Fax: (04) 496 2191

Email: central_ethicscommittee@moh.govt.nz

10 November 2008

Beverley Parton



Dear Beverley

The experience of urban Moari women and perceived delay in accessing women's health care in Aotearoa New Zealand: An exploratory study
Beverley Parton

CEN/08/09/049

The above study has been given ethical approval by the **Central Regional Ethics Committee**.

Approved Documents

- Information Panui, dated 1 November 2008, Version 1
- Participant Consent Panui, received 1 November 2008

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report

The study is approved until **31 July 2009**. A final report is required at the end of the study. The report form is available on <http://www.ethicscommittees.health.govt.nz> and should be forwarded along with a summary of the results. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments

It is also a condition of approval that the Committee is advise of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Sonia Scott
Central Regional Ethics Committee Administrator

Email: sonia_scott@moh.govt.nz

9 August 2010

Ms Beverley Parton


Dear Beverley

Ethics ref: **CEN/08/09/049** (please quote in all correspondence)

Study title: The experience of urban Māori women and perceived delay in accessing women's health care in Aotearoa New Zealand: An exploratory study

Thank you for your letter dated the 18th July 2010 enclosing documentation relating to the above named study. This documentation has been reviewed and approved by the Chairperson of the Multi-region Ethics Committee under delegated authority.

Approved Document

- Changes in the Information Panui

Please do not hesitate to contact me should you have any queries.

Yours sincerely



Jacqi Bartlett
Administrator
Central Regional Ethics Committee
Email: Jacqi_bartlett@MOH.govt.nz



MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGĀ TANGATA

Māori women, health care and perceived delay: An exploratory study

(Please keep this Information Panui for your future reference)

Kia Ora My name is Beverley Parton. I am a registered nurse who has worked in a Māori health setting for over eight years, and in the community for most of my working and family life. I am also a student undertaking research at Massey University, Wellington, as part of my doctoral study. I am really interested in the health of Māori whānau, and in particular Māori women. This panui is an invitation to you to be part of this study.

What I hope to achieve in the study I hope to hear the stories of your experiences about health and health services in Aotearoa New Zealand. I particularly want to hear what it has been like for you when you could not get to an appointment such as for a health check or for follow up at a hospital clinic. I hope your gift of knowledge can be used to help us work with Māori whānau.

Study participants I would like to hear from you if you are a Māori woman and could not get to an appointment at a hospital clinic or medical centre for at least three months at some time in your life. If you are interested in meeting with me to tell me your story about those experiences of health and health services please contact the organisation supervisor whose contact details are on the next page.

What will you do as a study participant?

- Meet with me for about an hour at a place convenient for you or we can meet in a private room at Kokiri Marae Health & Social Services
- If you wish at a later time, we can meet again and I will go over with you what was said at the first interview, and you will then be able to change, remove, or add anything.

You may choose to talk with me on your own, or with one or more support persons of your choice with you, or in a small group of women who meet the study's criteria (if there are sufficient who indicate this choice).

What will happen to the your story?

- Your story will be recorded, written down, and both securely stored. You may ask for the recording to be turned off at any time during the interview

Version 18 July 2010

1

Te Kunenga
ki Pūrehuroa

School of Health and Social Services
Wellington Campus, PO Box 756, Wellington 6140, New Zealand T +64 4 801 5799 F +64 4 801 2884 www.massey.ac.nz

- Your story will be treated completely confidentially and only seen by me as the researcher, by my supervisors, and by the research assistant who will have signed a confidentiality agreement to write it down from the recording
- The stories will be collected together and presented in such a way that no individual person will be recognised
- You will have the option of having a CD copy and a summarised written copy of your interview given to you if you have been interviewed on your own or with a support person
- When the study is completed the recording and written story will be stored securely at Massey University for 10 years and then destroyed
- You will have the option of having your recording and written story returned to you when the study has finished
- You may receive a summary of the findings when the study is completed if you indicate on the consent form.

What if you change your mind after taking part?

There is no compulsion for you to take part. You do not have to answer any questions you don't want to. You are free to withdraw up until the time you have verified the written interview copy at the second interview. If you withdraw then, your contribution will be destroyed or returned to you if you wish.

Contacts for other queries or concerns

Myself: [REDACTED]

My principal study supervisor: Associate Professor Annette Huntington, RN PhD Massey [REDACTED]

My organisation supervisor: Sharon Reid, Te Aitanga-ā-Māhaki, Manager, Kokiri Marae Health & Social Services [REDACTED]

If by participating in this research it brings up difficult areas for you, I would like to assist you to resolve any concerns. This could involve referral to a counselor if you wish. If I had a serious concern about your health I would seek your permission to liaise with your general practitioner for services or referrals.

Statement of approval

This study has received ethical approval from the Central Regional Ethics Committee.

Thank you for your interest in participating.

Nāku me te rere tonu o ngā mihi.

Beverley Parton

Pipiri 2011



Massey University

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
Te Kura Pūkenga Tangata

SCHOOL OF HEALTH
& SOCIAL SERVICES
Wellington Campus
Private Box 756
Wellington 6140
New Zealand
T 64 4 801 5799
F 64 4 801 2884
www.massey.ac.nz

Māori women, health care and perceived delay: An exploratory study

Interviewing Guidelines

1. Greeting: Kia Ora
2. Mihi
3. Karakia
4. Whakawhanaungatanga
5. Review Study Information Panui
6. Obtain written consent

Her stories may cover:

- General views of health for whānau and self over the life span
- Understandings of the different prevention/treatment roles of health services for women
- Experiences of the seeking of health care throughout their life including delay in attending women's health appointments
- Views of 'culturally safe' protocols for health services and practice—environment, privacy, confidentiality, shame, time issues—convenience of appointments, hurriedness of worker, use of technical terms, gender preferences
- Perception of any differences between their own health as Māori women and the health of women who are not Māori
- How the health of Māori women is seen as being position in Aotearoa New Zealand
- Whānau care and support by the women and for the women

Concluding by summary, then Karakia

Nā Beverley Parton



MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGĀ TANGATA

Māori women, health care and perceived delay: An exploratory study

Participant Consent Panui

I have read or had explained to me the details of the study in the Information Panui. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree / do not agree to the interview being recorded.

I wish / do not wish to have a CD copy of my recorded interview given to me if I am interviewed on my own or with my support person.

I wish / do not wish to have a summarised written copy of my interview given to me

I wish / do not wish to have data placed in an official archive

I wish / do not wish to receive a summary of the completed study

If I choose to be interviewed with anyone else I will keep anything they say completely confidential

I understand that the researcher may seek my permission to liaise with my general practitioner for services or referrals if she believes it is important

I agree to participate in this study under the conditions set out in the Information Panui

Signed: _____ Date: _____

Full Name (printed): _____



Massey University

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Te Kura Pūkenga Tangata

SCHOOL OF HEALTH
& SOCIAL SERVICES
Wellington Campus
Private Box 756
Wellington 6140
New Zealand
T 64 4 801 5799
F 64 4 801 2884
www.massey.ac.nz

Māori women, health care and perceived delay: An exploratory study

Transcriber's confidentiality agreement

I (Full Name - printed) agree to
transcribe the interview recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those
required for the project.

Signature: _____ Date: _____

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