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Medications and meanings in Māori households with chronic illnesses

By

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of

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*I dedicate this thesis to my tāne Caleb
and our beautiful boy Òkaire*



ABSTRACT

Domestic spaces have always featured as sites for health care. The home is increasingly referred to as a new therapeutic space within which chronic illnesses are managed within everyday life. This research explores the meanings and use of medications within four Māori households containing at least one chronically ill householder. A broad ethnographic approach was used to capture popular understandings and medication use in daily life. Multiple methods were used, including group discussions with household members, individual interviews, household mapping, and photographic and diary elicitation tasks. Findings shed light on the sources and uses of medications, householder knowledge of medications, communal practices of sharing, caring, rationalising use, grappling with side-effects and the management of illness. I consider what it means for householders to take medications themselves or give these to others, and the care-giving practices that feature in the everyday consumption of medicines. The research is based on the premise that medications are material objects with therapeutic uses that enter into and take on meaning within people's lives. Medications become culturally embedded phenomena that carry meanings and shape social relationships and practices with Māori households. As such, medications were used in a way that reflected the cultural values and bonds within the households. Within household relationships, medications were invested within meaning to show aroha, support and care. Within a Māori whānau context, the values of maanakitanga, rangatiratanga, and whanaungatanga were recognised as having an integral role in understanding the social practices with medications in each household.

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MĀORI GLOSSARY

<i>Aroha</i>	Affection, compassion, love
<i>Hapū</i>	Kinship group, clan, sub-tribe
<i>Harakeke</i>	New Zealand flax, native plant with long, stiff, upright leaves and dull red flowers.
<i>Hōhā</i>	Tiresome, bored
<i>Iwi</i>	Extended kinship group, nationality
<i>Kia ora</i>	Hello
<i>Kōhanga Reo</i>	Māori language preschool
<i>Kotahitanga</i>	A movement for self-government and national unity among Māori kinship groups during the 19th Century
<i>Kōwhai</i>	Small-leaved native trees noted for their hanging clusters of large yellow flowers in early spring
<i>Mana</i>	Prestige, authority, control
<i>Manaakitanga</i>	Hospitality, kindness, caring
<i>Manaakitia</i>	To support, take care of, give hospitality to
<i>Mātauranga</i>	Education, knowledge, wisdom
<i>Mauri ora</i>	Breath of life, life principle, special nature
<i>Pākehā</i>	New Zealander of European descent
<i>Pōhutukawa</i>	New Zealand Christmas tree, bear large, red flowers and have leaves which are velvety-white underneath

<i>Pupuri</i>	To hold, retain possession of, keep
<i>Pūriri</i>	A large spreading tree, having hand-shaped glossy leaves with 3-5 'fingers' and wavy margins, has pinkish-red flowers
<i>Rangatiratanga</i>	Sovereignty, chieftainship, right to exercise authority
<i>Rongoā</i>	Medication, remedy, drug
<i>Taonga</i>	Property, goods, possessions
<i>Te Ao Māori</i>	The Māori worldview
<i>Tikanga</i>	Correct procedure, custom
<i>Tohatohatia</i>	Capacity of whānau to share resources
<i>Tūranga</i>	Stand, position, situation
<i>Wairuatanga</i>	Principles associated with a spiritual embodiment
<i>Waka</i>	Allied kinship groups descended from the crew of a canoe which migrated to New Zealand
<i>Whakamana</i>	To give authority to
<i>Whakapapa</i>	Genealogy, lineage, descent
<i>Whakatakato</i>	Wise management and development of whānau resources
<i>Whānau</i>	Extended family, family group, a familiar term of address to a number of people
<i>Whanaungatanga</i>	Relationship, kinship, sense of family connection
<i>Whāngai</i>	Foster child, adopted child

MEDICAL GLOSSARY

<i>Accuretic</i>	Trade name for the combination medication, containing a fixed amount of quinapril and hydrochlorothiazide. The ace inhibitor widens blood vessels making it easier for the heart to pump blood, while the diuretic makes the kidneys pass more water and salt while retaining more potassium, which helps reduce high blood pressure.
<i>Agents affecting the Renin-Angiotensin System</i>	Class of medication used in the treatment of renal hypertension and predisposes patients to progressive chronic kidney disease and highly effective in lowering blood pressure in patients with essential hypertension.
<i>Antipsychotics</i>	Tranquilising psychiatric medication which is primarily used to manage psychosis (including delusions or hallucinations, as well as disordered thought), particularly in schizophrenia and bipolar disorder.
<i>Antiulcerants</i>	Group of medications used in the prevention and treatment of ulcer disease by providing reduction in the production of gastric acids.
<i>Arthritis</i>	Group of conditions involving damage to the joints of the body.
<i>Aspirin</i>	Medication used long-term, at low doses, to help prevent heart attacks, strokes, and blood clot formation.
<i>Atopic Eczema</i>	Inflammatory chronically relapsing, non-contagious and pruritic skin disorder.

<i>Beclazone</i>	Medication, which is a metered dose aerosol inhaler which delivers 50 micrograms of beclomethasone dipropionate.
<i>Benazepril</i>	Medication used to treat high blood pressure (hypertension), congestive heart failure, and chronic renal failure.
<i>Benzodiazepine</i>	Medication used to enhance the effect of the neurotransmitter gamma-aminobutyric acid, which results in sedative, hypnotic (sleep-inducing), anxiolytic (anti-anxiety), anticonvulsant, muscle relaxant and amnesic action. It is useful in treating anxiety and insomnia.
<i>Beta Adrenoceptor Blockers</i>	Class of medication used for various indications, but particularly for the management of cardiac arrhythmias, cardioprotection after myocardial infarction (heart attack), and hypertension.
<i>Blood Glucose Levels</i>	Medical term for the amount of glucose (sugar) present in the blood.
<i>Blood Pressure</i>	Medical term used to describe the pressure exerted by circulating blood upon the walls of blood vessels, and is one of the principal vital signs.
<i>Bronchodilator</i>	Medication that dilates the bronchi and bronchioles, decreasing airway resistance and thereby facilitating airflow.
<i>Bumetanide</i>	Loop diuretic medication, used to treat heart failure. It is often used in patients in whom high doses of furosemide are ineffective.

<i>Calcium</i>	Dietary supplement that is used to prevent and to treat calcium deficiencies.
<i>Cervical Cancer</i>	Medical term to describe a malignant neoplasm (cancer) in the neck of the uterus or uteri, which opens into the vagina.
<i>Cholesterol</i>	Waxy steroid metabolite found in the cell membranes and transported in the blood plasma. Cholesterol is an important component for the manufacture of bile acids, steroid hormones, and fat-soluble vitamins.
<i>Chronic Asthma</i>	Medical term to describe a chronic inflammatory disease of the airways characterised by variable and recurring symptoms, airflow obstruction, and bronchospasm.
<i>Chronic Hay Fever</i>	Medical term to describe an allergic reaction to pollen or dust. When an allergen is inhaled by an individual with a sensitised immune system, it triggers antibody production.
<i>Cranberry</i>	Dietary supplement used to prevent urinary tract infections.
<i>Digoxin</i>	Medication used in the treatment of various heart conditions, namely atrial fibrillation, atrial flutter and sometimes heart failure that cannot be controlled by other medication.
<i>Diuril</i>	Diuretic medication used to manage excess fluid associated with congestive heart failure.
<i>Dysphasia</i>	Medical term to describe a language disorder in which there is an impairment of any

language modality. This may include difficulty in producing or comprehending spoken or written language.

Epilepsy

Medical term used to describe a chronic neurological disorder characterised by recurrent unprovoked seizures. These seizures are transient signs and/or symptoms of abnormal, excessive or synchronous neuronal activity in the brain.

Ferrograd C

Medication which is used as an iron preparation containing ferrous sulphate and vitamin C.

Fibrillating Heart Condition

Medical term used to describe an autosomal dominant heart condition that causes disruptions in the heart's normal rhythm.

Fluid Retention

Medical term used to describe abnormal accumulation of fluid in the circulatory system or within cavities of the body.

Fluoxicillin Sodium

Antibiotic medication which is used to fight skin infections, where it kills bacteria or inhibits their growth.

Furosemide

Loop diuretic medication used to treat hypertension and edema often due to congestive heart failure or renal insufficiency.

Gall Bladder

Small organ that aids digestion and stores bile produced by the liver.

Gangrene

Medical term used to describe the death of an area of the body. It develops when the blood supply is cut off to the affected part as a result of various processes, such as

infection, vascular (pertaining to blood vessels) disease, or trauma.

Glipizide

Anti-diabetic medication used to lower the glucose levels in the blood.

Glycerine Cetomacogol

Medicated topical cream used to soften skin and moisturise. It is used to correct dryness and scaling of the skin.

Heart Attack

Medical term used to describe when blood flow to a section of the heart muscle becomes blocked. If the flow of blood is not restored quickly, the section of heart muscle becomes damaged from lack of oxygen and begins to die.

Hepatitis C

Medical term used to describe an infectious disease affecting the liver, caused by the hepatitis C virus (HCV).

Indapamide

Medication used in the treatment of hypertension, as well as decompensated cardiac failure.

Insulin

Hormone that is central to regulating energy and glucose metabolism in the body.

Levothyroxine

Medication which is a synthetic form of thyroxine (thyroid hormone), used as a hormone replacement for patients with thyroid problems.

Lipids

Broad group of naturally occurring molecules which includes fats, waxes, sterols and fat-soluble vitamins.

<i>Locoid Cream</i>	Trade name for medicated cream which is used as a topical steroid. Used in the treatment of rash, eczema, and dermatitis.
<i>Mastectomy</i>	Medical term for the surgical removal of one or both breasts, partially or completely. Mastectomy is usually done in the treatment or prevention of breast cancer.
<i>Metformin</i>	Oral anti-diabetic medication. It is the first-line medication of choice for the treatment of type II Diabetes.
<i>Mirtazapine</i>	Medication which is a tetracyclic antidepressant used primarily in the treatment of depression. It is also used as a hypnotic, antiemetic, and appetite stimulant, and for the treatment of anxiety, among other indications.
<i>Moduretic</i>	Medication used in the treatment of hypertension and congestive heart failure. Contains a combination of amiloride and hydrochlorothiazide.
<i>Nitrofurantoin</i>	Antibiotic medication usually used in treating urinary tract infection.
<i>Omeprazole</i>	Medication which is a proton pump inhibitor used in the treatment of dyspepsia.
<i>Painkiller</i>	Medication used to relieve pain (achieve analgesia).
<i>Panadol</i>	Trade name medication used as a mild pain reliever.

<i>Peak Flow Meter</i>	Small, hand-held device used to monitor a person's ability to breathe out air. It measures the airflow through the bronchi and thus the degree of obstruction in the airways.
<i>Phenytoin Sodium</i>	Medication that acts to suppress the abnormal brain activity seen in seizure.
<i>Potassium Chloride</i>	Dietary supplement. Potassium is vital in the human body and oral potassium chloride is the common means to replenish it.
<i>Prednisone</i>	Synthetic corticosteroid medication used as an immuno-suppressant, and affects virtually all of the immune system. It is used to treat certain inflammatory diseases and (at higher doses) cancer, but has significant adverse effects.
<i>Rheumatoid Arthritis</i>	Medical term used to describe a chronic, systemic inflammatory disorder that may affect many tissues and organs, but principally attacks synovial joints.
<i>Semi-incontinence</i>	Medical term used to describe the loss of regular control of the bowels.
<i>Simvastatin Sodium</i>	Hypolipidemic medication used to control hypercholesterolemia (elevated cholesterol levels) and to prevent cardiovascular disease.
<i>Steroid</i>	Medication which is given either in a short burst to stop serious asthma flare-ups or on a low dosage as maintenance for severe asthmatics to prevent symptoms.

<i>Stroke</i>	Medical term for the rapidly developing loss of brain function(s) due to disturbance in the blood supply to the brain.
<i>Symbicort</i>	Medication, which is a combination formulation containing budesonide and formoterol, used in the management of asthma and chronic obstructive pulmonary disease.
<i>Thyroid Gland</i>	One of the largest endocrine glands in the body. The thyroid controls how quickly the body uses energy, makes proteins, and controls how sensitive the body should be to other hormones.
<i>Type I Diabetes</i>	Metabolic disorder used to describe a form of diabetes mellitus that results from autoimmune destruction of insulin-producing beta cells of the pancreas. Type I diabetes is fatal unless treated with insulin.
<i>Type II Diabetes</i>	Metabolic disorder that is characterised by high blood glucose in the context of insulin resistance and relative insulin deficiency. Diabetes is often initially managed by increasing exercise and dietary modification. As the condition progresses, medications may be needed.
<i>Ulcer</i>	Medical term for a sore on the skin or a mucous membrane, accompanied by the disintegration of tissue.
<i>Urinary Tract Infection</i>	Reoccurring bacterial infection that affects any part of the urinary tract.

CHAPTER ONE: INTRODUCTION

Medications are one of the most widely used medical technologies, both for treating illness and for sustaining health. They also carry a significant cost to the health care system. PHARMAC reports the community drug bill for the year June 2008-June 2009 at \$653 million, which is a \$17.6 million increase on spending compared to the previous year (PHARMAC, 2008). Government subsidies on medications administered by PHARMAC are widening every year, with eight new medications being introduced in the 2008/09 period and with an estimated 30,400 new patients. 3.1 million New Zealanders receive taxpayer funded medications and over 35.1 million prescriptions were written in 2007 (PHARMAC, 2008). The top six expenditure groups for medications were Lipid modifying agents, used for raised cholesterol levels at a total cost of \$63.47 million; Antipsychotics, used for mental health disorders at a total cost of \$61.58 million; Antiulcerants, used to treat heart burn and stomach ulcers at a total cost of \$43.42 million; Beta Adrenoceptor blockers, used to treat heart disease at a total cost of \$32.01 million; Agents affecting the Renin-Angiotensin System, used to treat raised blood pressure at a total cost of \$31.19 million; and Diabetes medications, used to treat both Type I and II Diabetes at a total cost of \$31.06 million.

Considerable research has been devoted to issues such as adverse drug reactions, side-effects, and compliance (Barter & Cormack, 1996; Campbell, McCosh, & Reinken, 1983; Carrick, Mitchell, Powell, & Lloyd, 2004; Conrad, 1985; Ingersoll & Cohen, 2008). Despite studies showing that medicines are often not taken as intended by health professionals (Schoen, Downey, & Osborn, 2003), we know little about what happens with medications when taken home; why people do what they do with medications; or how medications are understood by people. Although more than 200 variables have been studied, none could be considered consistently predictive of compliance behaviours (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Compliance to prescribed medications is an ever present and complex problem. This is particularly prevalent for

those with chronic illnesses as they may have multiple symptoms, take high dosages of medication, face long-term treatment and take multiple medications (Wilson, Hutchinson, & Holzemer, 2002).

Research into the everyday meaning and use of medications is sporadic. However, what literature there is provides insights relevant to my study. Pound and colleagues (2005) synthesised studies on medicine taking and identified three styles of users; those who accepted medicines *readily*, those who accepted medicines *reluctantly*, and those who *resisted* medicines, with each style leading to different medication usage. Shoemaker and Ramalho de Oliveira (2008) reviewed studies of medication use experience, concluding that different meanings given to medications were important for explaining variations in medication practices and needed to be taken into account by health professionals. Such studies provide useful indications of the complexities of meanings and everyday practices surrounding medication use.

My thesis is based on the premise that medications are material objects with therapeutic uses that enter into, and take on meaning within people's lives. They are culturally embedded phenomena that carry meanings and shape social relationships and practices. As van der Geest and Harden (2006, p. 1) note "Things acquire meaning, when they enter into the life of people". I will investigate Māori households with people who have a chronic illness, to explore participant understandings of medications and their medication-taking practices. The specific research aims are to:

- I. Explore householder knowledge of medications, how medications work, and what it means to take medication.
- II. Document social practices involving medications within households, such as how, when and where they are used, and how they are accessed and distributed.

The primary objective of this research is to advance knowledge about the meanings of medications in Māori households and the socio-cultural practices that surround medication use.

Documenting a clear understanding of medication-taking practices for Māori, and how these are incorporated into their daily lives, may enhance efforts to support the health needs of Māori and the development of services and interventions that support whānau in the management of chronic illness.

This chapter begins with an exploration of the literature on medications and chronic illness, providing an overview of the current health picture of Māori. Next consideration was given to Māori cultural concepts and values and how these set a context for the meaning and use of medications within Māori households. I then turn to the scholarly literature pertaining to chronic illness experiences, discussing its impact on identity, biography and goals, and the ways in which people approach treatment are examined within the context of the management of ailments with medications. Next, I consider the processes of meaning making within a Māori social and cultural context. This provides a framework for considering connections between assessing medications; medication knowledge; medication practices, including the perspective of compliance and medication related interactions, all of which contribute to the meanings of medications to individuals and their households.

Māori and chronic illness

In the last 40 years, almost all of today's medicines, medical equipment and medical technologies came into use (Weisbrod, 1991). The new technologies have revolutionised the ways in which healthcare is practiced. As the population ages the prevalence and diagnosis of chronic illness rises, diabetes, heart disease and asthma have become the leading cause of illness, disability and mortality (Gerritsen, Stefanogiannis, Galloway, & New Zealand Public Health Intelligence, 2008). Today's health system remains overly devoted to dealing with acute and episodic healthcare needs. Concurrently, the treatment and long-term care and support for chronic illnesses are increasingly being met in domestic settings (Weisbrod, 1991).

Chronic illnesses are the leading cause of preventable morbidity and a key factor in life expectancy disparities between Māori and non-Māori populations (Gerritsen et al., 2008). Chronic illnesses can function as barriers to independence, participation in the workforce and social functioning. Such ailments can have an adverse affect on patients and their families as they limit the daily lives of those affected and those who support or depend on them. According to a number of studies, Māori have different health outcomes in comparison to the general population. When compared with people of European descent within the same income bracket, Māori were significantly less likely to; have seen a doctor when unwell, received adequate tests, and accessed medication (Schoen & Doty, 2004). In the Portrait of Health (2008), statistics for Māori indicated that the prevalence of high blood pressure and diabetes was two-and-a-half times higher for Māori than non-Māori. Māori women had twice the likelihood of having ever been diagnosed with ischemic heart disease and were 40% more likely to be taking medication for asthma than women in the total population. Māori children were four times more likely to die from asthma than New Zealand European children. Māori men were 15% more likely to develop arthritis compared to men in the total population and they die up to 14 years earlier than other New Zealand men, often from heart disease.

Research suggests that Māori do not receive the same health management support for chronic conditions. For instance, Māori have significant difficulties in accessing specialist support for cancer when needed, and higher hospitalisation rates than non-Māori (Ministry of Health & Wellington School of Medicine, 2005). Māori also have lower referral rates for surgical and specialist services than non-Māori and experience lower levels of quality hospital care than non-Māori (Ellison-Loschmann & Pearce, 2006). Diabetes (Baxter, 2002), heart disease (Westbrooke, Baxter, & Hogan, 2001), and cancer (Robson, Cormack, & Purdie, 2006) are all examples where Māori have delayed referral and treatment and received less intervention.

Socio economic status is another important factor when considering the prevalence of chronic illness among Māori. People on low incomes are generally more likely to develop chronic illnesses (New Zealand National Advisory Committee on Health Disability, 2007). Between 1981 and 2001, Māori were disproportionately represented in lower socio-economic strata and consequently, disproportionately affected by the health consequences of lower socio-economic status (Statistics New Zealand, 2007). The management of chronic illnesses have significant financial deterrents that extend beyond direct health costs. Households on lower incomes are more likely to enter into cycles of poverty and poor health (New Zealand National Advisory Committee on Health Disability, 2007). For example, living standards are lower among families with high numbers of doctor visits for illness, moreover these families become restricted in their social and economic participation due to a family member's serious health conditions (Ministry of Social Development, 2009).

Māori face many disadvantages well beyond the health effects attributed to economic status. Māori experience unequal access to the health system, which contributes to health inequalities between Māori and non-Māori (Fawcett, 2006). The decades of disparity report by the Ministry of Health, Wellington School of Medicine and Otago University (Fawcett, 2006), found that Māori have poor access to resources and facilities, which help, prevent, treat and manage illness before it progresses to a chronic state. Life expectancy has consistently increased in New Zealand since the 1950s; however, there remains an 8.6-year gap between Māori and non-Māori (Ministry of Social Development, 2009). Consequently, the health inequalities gap is widening between the Māori population and the general population (Ministry of Social Development, 2009).

The prevalence of chronic illness among Māori is an on-going issue, and medications are a major part of the way in which technology is used to respond to chronic illness. Presently no one has studied medications within Māori households, what meanings they give to their medications and how it affects social practices. Studies have been conducted on chronic illness among Māori in which they focus on specific ailments.

Examples include barriers to health care for those Māori diagnosed with diabetes (Baxter, 2002; Simmons, Weblemoe, Voyle, & Prichard, 1998), health seeking behaviour for Māori men with prostate cancer (Williams et al., 2003) and prevalence of lung cancer among Māori (Harwood, Aldington, & Beasley, 2005).

The main findings of such studies include barriers to services for Māori, provider communication and patient knowledge. A number of organisational issues were also identified including a lack of community-based services, transportation difficulties, the timing and availability of services, appointment systems, the lack of appropriate educational and promotional material, and the universal Western approach. The universal Western approach to health care is based on the foundation that irrespective of wealth, socio economic status or ethnicity, people have equal access to services, ignoring obstacles that are faced by ethnic groups (Reid, Robson, & Jones, 2002). Staffing issues were also raised such as the under-representation of Māori in the health professions. The characteristics of non-Māori health staff were critiqued including their perceptions of, and attitudes about Māori patients and a lack of appropriate provider-patient communication. Further, personal or community level issues came to the fore highlighting the socio-economic position of many Māori making healthcare simply unaffordable. Lastly, individuals may have had previous negative experiences with the healthcare system and/or perceptions of bias, such as non-Māori health services not being seen as acceptable or clients hearing negative comments from others.

Illness can be conceptualised as encompassing both a physical disease and a person's subjective perception of the objectively defined disease (Radley, 1994). Understandings of illness vary significantly around the world. Of the thousands of published studies about illness, most discuss the notions of disease and illness within their different social, environmental and political contexts (Hughner & Kleine, 2004). However, there are clear distinctions between definitions of illness and disease. Radley (1994) defined disease as the pathological changes in one's body,

and illness as the experience of disease and sickness as a social role that sufferers occupy in relation to the healthy. Further, one may be ill, but not be considered to have a disease or to be sick; conversely, one may have a disease without feeling ill.

The Ministry of Health (2004) defined chronic illness as “a physical or mental illness that has lasted, or is expected to last, for more than six months. The symptoms may come and go or be present all the time” (p. 4). In the context of this research, chronic illness was defined as a long-term, often permanent, and progressive illness, where an individual is in a state of poor health. However, it is important to acknowledge that, an individual’s subjective perception of their health status is a vital part of recognising if one has a chronic illness.

Illnesses are understood and take shape within broader social, environmental and political contexts that partially shape everyday life. Illnesses affect the lives and daily routines, not only of the person who is ill, but also of people who are connected in any way to the affected person (Lyons & Chamberlain, 2006). Health psychology has viewed chronic illness as a life crisis requiring change and adjustment, as people often need to make considerable adaptations in their lives. Such adjustments include medication management, dietary and exercise changes and pain management (Radley, 1994). These adjustments may also encompass psychological responses to the illness which are specific to their social situation, and context, identity changes, maintaining or changing ones personal appearance or self-image, sustaining social relationships with friends family and colleagues, and planning for an uncertain future (Lyons & Chamberlain, 2006). Despite these adjustments experienced by most chronic illness sufferers, many do not seek formal assistance. Conversely, they rely on their own personal and social resources to find solutions (Herek, Costa, & VandenBos, 1990). These issues are clearly relevant to the ways in which Māori households experience, react to and manage illness in culturally patterned ways.

Culture, illness and medication

Part of adjustment to, and management of, illness is culturally based. The fundamental characteristics of culture assume many forms varying from behavioural practices that are held and maintained between people such as family interrelationships, economic exchanges, material artefacts such as tools and building structures, to intangible concepts such as values and beliefs (Barnard & Spencer, 2002). Culture encompasses a system of shared beliefs, values, customs, behaviours (Ferraro, 2006) that often involve the use of material objects that take on cultural meanings and communicate shared values (Barnard & Spencer, 2002).

Medications are cultural objects, their meaning, interpretation and use are the products of their specific cultural contexts. When in the hands of particular groups, medications often take on new meanings. In a Māori cultural context, the function of medications remains in many respects the same as in Pākehā culture to improve health, medicate symptoms and ward off illness. However, in terms of the use and social practices around medications, these objects come to represent cultural meanings and values. For example, when a person is caring for another, such as a daughter caring for her elderly parent, an object such as a pill, which is exchanged and administered between the two people begins to present itself as a symbol of that relationship. A relationship that is culturally defined and driven by cultural values like manaakitanga and whanaungatanga (Ritchie, 1992).

A person's culture provides resources for making sense of the world and prescribes social roles for its members, shaping "how they show feelings, express emotions and distress, and experience conflict in behaviour, thought or action" (Baxter, 2002, p. 65). To explore what medications mean to Māori households, consideration must be given to the cultural context of a Māori household. In the remainder of this section, the concepts of tikanga, whānau, whanaungatanga, maanakitanga, rangatiratanga and kotahitanga will be considered in relation to medication use. These concepts prescribe principles and wisdom Māori use in

everyday life to varying degrees, informing people's behaviours and governing responsibilities and relationships (Collins & Willson, 2008).

Hirini (1997) identifies that Māori social structure is based on core values governed by tikanga. Tikanga provides the guidelines, manners, rules and correct procedures that are developed and performed in the daily lives and practices of whānau. Whānau are continually changing and evolving to adapt to modern society where values and beliefs are tested and reinforced. The word whānau is used in a number of contexts and it is important to define what it means in terms of the relationships presented in Māori households.

Whānau is a concept that is used by Māori with wide definition and reference (Metge, 1995). Whānau is based on whakapapa and kinship ties, and provide an environment in which social knowledge and relationships is learned and maintained (Barlow, 1991). Stewart-Harawira (1995) describes whānau as the foundation for Māori social interaction and social assimilation, which encompasses mātauranga Māori, mauri ora and tūranga Māori.

The concept of whānau can be described as a definable object or structure based on descent, a cause or a collection of ideas (Metge, 1995). Whānau can be interpreted as a basic family structure with a mother, father and children. It can also stretch to encompass extended family members such as aunties, uncles and cousins, partners and whāngai members (Broughton, 1993; Metge, 1995). Another interpretation of whānau is based on genealogy or whakapapa, describing the ancestral link, including both patriarchal and matriarchal lines regardless of whether they are living or have passed away (Barlow, 1991). Metge (1995) also discusses how whānau is not limited to descent or whakapapa, but has an active component whereby whānau members are actively involved in the collective group. The concept of whānau can also be described as a belief system of reciprocity and commitment to benefit members of that group, applying the whānau values of aroha, mutual

support, cooperation and unity (Gibbons, Temara, & White, 1994; Metge, 1995).

Whānau can include groups that have a common cause or interest such as, a school classroom, Kōhanga Reo and recreational group in which they are associated through common environments (Metge, 1995).

Considering the various definitions of whānau, its description varies according to context (Metge, 1995). Based on the household focus of this research whānau is referred to as a kinship network based on whakapapa, including spouses and whāngai members who actively participate in whānau activities. The practical implications of values within a whānau are vitally important to the interpretation of Te Ao Māori as whānau membership involves a range of roles, responsibilities, commitments, and a number of functions.

Whānau is the fundamental kinship arrangement that supports the rearing of children in the Māori world. Whanaungatanga refers to relationships we have with others, related by whakapapa or otherwise (Nikora, 2007).

Whanaungatanga describes the bonds and commitments made to preserve the integrity and strength of the family. The wellbeing and success of a person is reflected in their ability to support and nurture their whānau. Furthermore, a strong healthy whānau is a reflection of its qualities and strength of the individual members. The bonds and commitments to other whānau members is an important component in explaining social relationships and behaviours.

Hirini (1997) describes whanaungatanga as a value that strengthens the commitment whānau members have towards each other.

Whanaungatanga provides structure within the social hierarchy, where it can help determine and identify individual's rangatiratanga by drawing on ancestral links to determine ones mana (Nikora, 2007). Whanaungatanga is very significant as it both establishes, and sustains, tribal identity (Ritchie, 1992). It is concerned with the acknowledgment and management of relationships and "gives meaning to these relationships

across time and place.” (Nikora, 2007, p. 77). As a value, it is also influenced and boosted by the value of *maanakitanga*.

The functional basis of *whanaungatanga* is the ability of the *whānau* to empower (*whakamana*) and encourage each other to reach their goals and contribute to the community. *Whanaungatanga* encourages the *whānau* to guard and preserve its assets (*pupuri taonga*) for future generations, such as land, heritage and heirlooms (Durie, 2001). *Whanaungatanga* is also about the *whānau*’s capacity to plan as it allows the *whānau* to see past present moments and to prepare for future challenges that they may face in order to revitalise, preserve and promote Māori culture, values and language (Durie, 2001).

Manaakitanga is the practice of reciprocal caring. Caring for another creates a sense of duty and responsibility whereby an individual is affirming they are a part of something larger than themselves; a part of a *whānau*. The reciprocal nature of caring for another need not be repaid immediately, rather, there is simply faith that one day it will (Ritchie, 1992). The major components of *manaakitanga* include the act of loving concern, the gift of exchange and hospitality, an act of generosity and the gift that returns a gift. *Manaakitanga* embodies much of the processes that occur when *whānau* members care for each other within their respective households (Hirini, 1997). *Manaakitanga* describes the process in which one performs and expresses *aroha*, hospitality, mutual respect and generosity, while upholding the person’s *mana*, as it has equal or greater importance than their own (Winiata, 2007).

The functional basis of *manaakitanga* is the ability of the *whānau* to care (*manaakitia*) and share (*tohatohatia*), as the young and old are cared for, sick and disabled are looked after and those who require resources are replenished. *Maanakitanga* encourages self-sacrifice for the betterment of the collective group. The capacity to share within the *whānau* depends on the generosity and sense of collective responsibility (Ritchie, 1992).

Rangatiratanga, as mentioned above, can be determined through *whakapapa* whereby a person can hold status. Ritchie (1992) explains

that rangatiratanga is not acquired by birth alone, but can also be obtained through respect by illustrating a certain skill and talent whereby it “draws from the spiritual dimension an additional boost of power or strength and mana” (Ritchie, 1992, p. 70). Rangatiratanga is about self-determination and self-agency, the capacity to control one’s future and to decision-make in this regard. Being self-determining within whānau is an important value in which recognises the importance of individuality, while respecting the value of kotahitanga, collective responsibility.

Kotahitanga is described as the principals associated with a collective unity considering the complexity of status, history, kinship. It is a central value that informs Māori culture in which it recognises individual’s prominence while also considering the needs of the collective group. The functional basis of Kotahitanga is achieved when whānau members invest time and energy in getting to know each other, work through differences and accepting responsibility for each other’s actions (Metge, 1995).

Collectively, these values can provide a basis of understanding the Māori cultural context, where it can inform household behaviours with varying degrees, as each Māori household can interpret and play out these values in different ways in relation to the use of medications. Medications are usually a necessary part of living with a chronic illness. In a Māori cultural context, medications can hold individual and collective meaning, they can be understood as functional objects, to better and maintain health and prevent illness. Within relationships, they can be invested within meaning to show aroha, affection and manaakitanga. Interpreting such actions as aroha lies in the cultural context of the household, where Māori values are interpreted and practiced, providing insight and understanding into behaviour, practices, and responsibilities.

Experiences of chronic illness

The experience of chronic illness is an important part of understanding the broader context of a person’s identity and life (Frank, 1995). It involves a process of learning, coping and the (re)negotiation of personal and

professional relationships. Understanding the different ways in which people cope, manage and live with chronic illnesses can help inform the social context in which medications have meaning in the lives of people. The chronic illness experience begins with the individual circumstances that led them to being diagnosed with a chronic illness. The journey can begin from the symptoms they experienced, or did not experience, through to the circumstances that led them to seeking medical attention. These can be influential factors towards the reactions of the person's ability to cope with diagnosis, where they may have had no previous knowledge of, or clue about having any illness, through to being totally aware of the medical circumstances that lead them to a diagnosis of a chronic illness. Pinder's (1990) study of recently diagnosed patients with Parkinson's disease described three kinds of roles, the *seekers*, *weavers* and *avoiders*. *Seekers* sought as much information as they could on the diagnosed illness, which at times led to anxiety as some questions simply could not be answered. *Weavers* sought information on occasion and would selectively construe information that suited them. *Avoiders* chose to ignore the diagnosis all together and live in ignorance of the implications of the disease. In this section, chronic illness experiences are explored in relation to issues of identity: biographical disruption, goals and motivations, coping, medication management, the efficacy of medication, and compliance with taking medications and ageing.

Shoemaker's (2008) study of chronic illness experiences captured participant's descriptions of their journey with medications, their bodily effects, and how they tried to exert some kind of control over their medications. The research provides an informative account of an individual's experience of medication use. Common themes emerged from the participant accounts. Participants discussed their first encounter with medications and explored the positive and negative effects medication had on their body. Participants also presented fears around the perceived need for medication and increased risks of dependency. Lastly, participants discussed accounts of trying to exert control over their situation and medication-taking practices, by altering the use and

administration of medication in accordance with medical advice. Exploring one's medication experiences and accounts can inform and enrich the understandings of the meanings that medications hold for those who have a chronic illness.

Studies such as those by Anderson and Bury (1988), Chamberlain and colleagues (2007), Charmaz (2006), Cohen, McCubbin, Collin, and Perodeau (2001) demonstrate that the meanings and understandings of medication are not only shaped through personal experience, but also through social experiences and relationships. Radley (1994) acknowledges that chronic illness affects the individual on two different levels, the physical and personal. The social consequences of having a chronic illness can impair one's mobility and performance, as one may have to alter their physical activities and change their pace of lifestyle. Radley (1994) notes that the experience of chronic illness is very different to those who are temporally ill, as a person's self-image is permanently changed. For instance, modifications may be made to their image and/or the way they conduct themselves to hide or accommodate symptoms.

Dealing with a chronic illness can also impact on a person's unique identity, as their perceived state of health changes to a person that has to live with an on-going illness (Frank, 1995). Identity refers to the way an individual characterises, performs, locates and differentiates their sense of self from others (Viswanathan & Lambert, 2005). Chronic illness can disrupt plans, performances, and the meanings that contributed to a person's self-perception. For example, the application of medications in one's life may require adjustments where a person may need to find an appropriate place to administer and store their medications as they would prefer others to not find out they were unwell. This can also include storing medications away when guests come over to one's house. Identity can also become a way in which people wish to define themselves, whereby wishes can become intentions, goals and objectives (Burke, 1980). In contrast to this, the chronically ill can feel a sense of loss, and lowered sense of value.

Another impact chronic illness can have on one's identity and life is the concept of biographical disruption (Frank, 1995). Biography is related to one's perceived life course. A chronic illness disrupts and dislocates a person's sense of identity, biographical time and normal bodily functions (Corbin & Strauss, 1987). When one has a chronic illness, the individuals sense of health, life span, achievement in life-goals, and responsibilities are disrupted. Any present or future related stress, suffering or decisions are compared to past experiences, present condition and future promise, invariably affecting the remainder of the person's life (Radley, 1994; Viswanathan & Lambert, 2005). It is important to acknowledge that not all chronic illnesses are the same as individual symptoms, experience of pain and the deterrent to one's health may differ. For example, in the short term or initial stages, people with chronic asthma, diabetes or chronic eczema might not perceive these conditions to be as life threatening as those with heart disease or cancer (Radley, 1994). Another perspective to consider is those who are posed with high risks of contracting a disease. For instance, a person may have high blood pressure or high blood sugar levels, which increases their risk of having a heart attack or developing diabetes. This may result in increased vigilance by the person affected by changing their diet or mentally preparing for the disease (Radley, 1994). Therefore, the chronic illness symptoms, severity, treatment side-effects and disease progression are all prominent features for those who are affected.

An important part of learning about the influences chronic illness has on a personal biographical journey, is the disturbance it can cause to one's life goals and motivations. An individual's goals and motivations are key contributing factors in a person's treatment, whether these are shared with the medical professionals or not, they can take precedence over medical advice and motivations to slow or reverse their illness. Viswanathan and Lambert (2005) state that people with chronic illness are largely motivated to reduce and/or treat the progression of their illness. Therefore, if a recommended treatment is perceived to aid in curing or reducing their symptoms and/or enabling them to return to some kind of normalcy, then

the recommended treatment is more than likely to be followed (Viswanathan & Lambert, 2005). If the treatment is perceived to obstruct ones valued pursuits, like affecting independence such as stopping a person from driving, then recommendations may be altered or ignored (Viswanathan & Lambert, 2005). Perceived rational treatment options recommended by medical professionals can sometimes be over ruled by the persons own rationality in the context of their beliefs, motivations, goals, responsibilities and preferences (Adams, Pill, & Jones, 1997; Conrad, 1985). Disruptions to a person's goals and motivations can both defeat or invigorate a person to make the most of their situation.

Chronic illness can impose a number of physical, practical and psychological challenges. These may include adjusting to bodily changes from the illness and/or adverse affects from medications. Practical issues may include adjusting material surroundings to accommodate reduced mobility, managing work and social obligations. Psychological issues may involve not being able to cope with the adjustment and developing depression and/or anxiety (Corbin & Strauss, 1987; Radley, 1989; Voysey Paun, 1975). Herek and colleagues (1990) found in their study that most chronic illness suffers do not seek professional help to cope with the present and foreseen challenges, rather, they more than often rely on their own internal and social resources to cope. To some, the diagnosis of chronic illness can become a frightening, challenging and intimidating journey and at times can lead to the initiation of coping strategies (Herek et al., 1990).

Coping strategies encompass people's abilities to face and deal with responsibilities, problems, or difficulties that are environmental and internal (Oxford University Press, 2000). Such strategies can include *problem solving* which include seeking out and using professional help or social support networks, such as family and friends (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992); *distancing*, which can involve efforts to distance oneself from a stressful situation, which also included avoiding certain stressful situations (Dunkel-Schetter et al., 1992); *positive focus* which is described by the efforts to find meaning in ones experiences,

such as feeling like you are going through this experience to help others who may be going through same situation (Dunkel-Schetter et al., 1992); *escape*, wishing that circumstances would change, or luck would come their way (Dunkel-Schetter et al., 1992); *denial*, refusing to acknowledge there is an illness and ignoring the symptoms and progression of the illness (Meyerowitz, 1983); *minimising*, choosing to ignore or play-down the pain or discomfort experienced, this may enable the person to preserve their healthy image, however, this becomes more difficult as the illness progresses (Charmaz, 1995); and *behavioural responses* such as using substances to avoid the situation or reality such as eating, drinking alcohol, smoking and taking illegal drugs (Dunkel-Schetter et al., 1992; Dunkel-Schetter, Folkman, & Lazarus, 1987). As people progress through their journey with chronic illness, their coping strategies fluctuate and change, as people can go through phases of denial, acceptance and then retreat back to a state of denial. The development and use of coping strategies illustrates how households respond to the realities of illness. Individuals experience with chronic illness can range from the transformation of one's self-perception, biographical outlook, valued pursuits and coping strategies. However, another important factor is the introduction and integration of medication into their everyday lives.

Meaning, use and placement of medications in the home

The purpose of this study is to explore what medications mean to Māori households, with members living with chronic illness. To identify, interpret and understand what medications mean to Māori households, one needs to understand how meaning is developed for individuals and families through social interactions. This research is based on the assumption that the negotiation of meanings is a multi-faceted and on-going process influenced by an individual's experiences, his or her internal and external dialogue, conversations with others, emotional responses, actions, education, culture and wider society (Credo Reference Firm, 2006; Hutchinson Firm, 2008; Pickett, 2000). Through social interactions, thought and behaviour are constructed in the exchange of symbols

between individuals and collectives (Cohen et al., 2001; Credo Reference Firm, 2006). This section explores previous research on the meanings of medications and use. The construction and comprehension of meaning is explored through the lens of social constructions and symbolic interactionism. The section then discusses the management of chronic illness in the home and how spaces function or impede medication use. As chronic illness can become consuming in a person's life their homes can become reconstructed as therapeutic spaces. Within these therapeutic spaces, routines are developed and maintained within homes and relationships become important influences to these routines. Medication use is then explored, as the practices and performances with medications reflected the associated values and meanings. Furthermore, obtaining knowledge on medication is covered as it provides an important indication that medications are vital objects within the patient's lives. Lastly, literature on medication compliance will be examined, as a perspective it enables insight into the various capacities of patients, including ones personal and cultural beliefs and understandings, which may impact on the use of medications.

Due to the complex nature of meaning making, philosophical stances and theories have been developed to explain the processes involved. Social constructionists view meaning as a 'construction' rather than a 'discovery' (Crotty, Schwandt, & Arens, 2001). The world and objects in the world only have meaning when human consciousness engages with them. Without human interaction in the world, there is no meaning, objects that exist in the world, such as a road, no longer can be associated with the name, purpose or context that was once given by humans (Crotty et al., 2001). The social constructionist theory considers how a social phenomenon develops within a social context. The theory acknowledges that meaning is not purely objective or subjective, it is based on the relationship of the object within the world and the social context in which it was constructed (Crotty et al., 2001). The creation of meaning is developed and interpreted within a social context on differing social levels, such as interactions between people, spaces and objects within

households, communities and wider institution, professions and society (Crotty et al., 2001; Nightingale & Cromby, 1999).

People's understandings of illness, disease and good health states are dynamic and sometimes jumbled, shifting in response to personal experience and circumstances, such as emotional states. Although most patients do not have free access to biomedical knowledge, they do not necessarily come to the doctor-patient encounter as empty vessels passively awaiting the wisdom of the doctor (Blaxter, 1979). Popay and Williams (1996) stated that lay people go through a "systematic process whereby experience is checked against life events, circumstances and history. They acquire an 'expert' body of knowledge, different from but equal to that of professionals in the public health field" (p. 760).

Medications are material objects that encompass both medical, personal and familial meanings for householders. Medications have "social lives" as well as pharmacological lives (Whyte, van der Geest, & Hardon, 2002) and once in the hands of people they can represent, not only relief from suffering or the maintenance of health, but also identity, morality, relationships, care, healing and hope, amongst other things (Cohen et al., 2001; van der Geest & Hardon, 2006). For something to have meaning, it must have value or significance to a person. Herbert Blumer developed a theory called 'symbolic interactionism,' which provides a conceptual context of understanding the relationships between subjective experiences and behaviour (Kimmel & Mahler, 2007). It is based on the premise that people use and act towards objects based on the associated meanings they have been given. These interactions are developed through social interaction with one's household, community and wider society. These meanings are interpreted and relayed to others through the individual interacting with the objects (Kimmel & Mahler, 2007). It is therefore important to understand the meanings people associate with medications to gain insight into their related behaviours. The home is one of the primary places that give shape and meaning to people's lives. Few studies have explored the practical implications of chronic illness management in

the home, as it becomes a site for long-term care (Imrie, 2004) and medication use.

The meanings given to medications and the use of these substances are also influenced spatially. For example, the structure of the home can impact on where to medications are placed. Homes and the rooms within them are built to accommodate the functional needs of people, such as a kitchen to cook meals in and a bedroom to sleep in. Hockey (1999) states that the construction of a home is based on positive aspects of life such as autonomy, companionship and security but deny other aspects of domestic life such as illness, disability and dying. When one has a chronic illness, the functional spaces in the home need to accommodate the storage and placement of medications.

Homes are increasingly being reconstructed as therapeutic spaces. Dyck, Kontos, Angus, and McKeever (2005) term the process of changing ones home into a site for care as 'homespace' where the home becomes a "material practice of care provision with medically defined needs" (p. 174). In medication management, routines are considered a vital part of keeping up with everyday life and maintaining long-term compliance (Haslbeck & Schaeffer, 2009). Routines can be described as a course of action that is followed regularly, in which they can be conscious or subconscious behavioral patterns which are used to organise and coordinate activities (Brooker, 2002; Zisberg, Young, Schepp, & Zysberg, 2006).

Studies also suggest that social networks such as friends and family provide more support in developing and maintaining routines in the home than health professionals (Gordon, Smith, & Dhillon, 2007; Reid et al., 2006). These studies indicate that practical support from social networks such as, reminding loved ones to take medication, designing easily accessed storage places and developing memory joggers are significant factors in the maintenance and support of productive routines (Gordon et al., 2007; Reid et al., 2006). Studies have also shown that risk factors are apparent when managing medications and risk increases with the complexity of the medication regimes. The more complex the regimen the

higher the risks of confusion, duplication and non-compliance (Conrad, 1985).

The meaning of medications is complex. For instance, the introduction of medications can represent dependence as one may need to rely on the medication to stay well, or, in contrast, independence, as it may relieve symptoms which otherwise restricted and confined interactions in the world (Adams et al., 1997; Conrad, 1985; Montagne, 1988; Nichter & Thompson, 2006; Rogers et al., 1998). Research indicates that individuals approach medications differently therefore, the meanings they associate with medications can also be various. Factors that contribute to different approaches include how long they had been on medication, the severity of their illness, and the adverse effects they experience. A number of studies (Gallant, 2003; Haslbeck & Schaeffer, 2009; Pinder, 1990) indicate that participants experiment with their medications by altering their treatment regimes. Patients find creative ways to manage their medications enabling them to gain a sense of control, such as changing administration times to suit one's lifestyle, reducing dosage amounts to manage side-effects (Adams et al., 1997; Charmaz, 2002; Haslbeck & Schaeffer, 2009; Ockleford, Shaw, Willars, & Dixon-Woods, 2008; Shoemaker & Ramalho de Oliveira, 2008), accessing medication and gaining knowledge and compliance. Medications have the ability to consume one's life, as they demand time, thought and consideration. Patients in these studies reduced the dominance of medication use and administration, by treating medication use as flexible and adaptable products, despite the consequences of reducing the effectiveness of the medication.

Obtaining knowledge around the use, application, and storage of medications, is an important part of understanding what medications mean to a person and a household. Obtaining knowledge on medications indicates that they are an important part of a person's life, as this takes time, motivation and initiative. Gaining knowledge allows the user and their carers to become fully informed of medications, its bodily effects and allows the users to become informed decision makers in relation to their

own health (Read & Wuest, 2007). Users and carers become empowered through knowledge, giving them a sense of knowing and reassurance about the outcomes of medication use and other medical decisions and are better mentally prepared for the future (Read & Wuest, 2007).

Knowledge and in particular the capacity to access that knowledge, contributes a great deal to a person's ability to take some control over a chronic illness. Another important factor in gaining control is the notion of compliance or non-compliance, where people go against medical advice and follow their own regimen, application and practices with medications. Compliance provides a perspective of use that enables researches to explore the various practice and behaviours with medications, where these behaviours can inform the meanings medications have in their everyday life.

Compliance is a perspective, usually from the viewpoint of medical professionals, where patients are advised to follow medical advice and prescriptions when taking medications. Compliance is a helpful way of viewing everyday practices that emerge around medication taking. A review of quantitative psychological research into compliance covering three decades concluded that, rather than being a static or fixed phenomenon, compliance is better considered as a fluctuating choice that is rationalised in the context of everyday life (Chia, Schlenk, & Dunbar-Jacob, 2006; Vermeire et al., 2001; Wilson et al., 2002). Earlier research by Dowell and Hudson (1997), New Zealand National Advisory Committee on Health Disability (2007), and Vermeire and colleagues (2001) reveals a range of understandings and practices people have with their medications such as: a varied knowledge base around the role of medication in peoples treatment regimes, discontinuing medication when they felt well, stockpiling medication for future use, and sharing medications with others who have similar conditions or symptoms.

Recent studies (Chia et al., 2006) show that compliance is a multifaceted role associated with various capacities including memory recall, problem-solving abilities, as well as personal and cultural values and beliefs.

Kairuz and colleagues (2008) study on identifying compliance issues, described how medication users would alter medication labels and transfer medicine into other containers, which was not advised by medical professionals. Such practices were introduced as participants had trouble swallowing the pills or found the medication container did not meet their specific needs. Other reasons for not taking medication included cost and adverse side-effects. Further, Pound and colleagues (2005) synthesis of studies on medicine taking suggest there are classes of patients; those who accept readily, accept reluctantly or resist medicines, each of whom used medications in different ways. Studies have also shown that patients did not view their medication practices as being non-compliant, as while medical advice was considered, other social and cultural factors were seen as having higher priority (Adams et al., 1997; Urquhart, 1994).

Vermeire et al (2001) recommends that the social and cultural context of medication users and their carers should be central to any medical decisions made by health professionals. Compliance should be viewed as a flexible and realistic aim. Medication users especially those with chronic illness, should be encouraged to make decisions about treatment options that are more suitable to their lifestyles, beliefs and personal circumstances (Vermeire et al., 2001). An important feature in the application of medications in ones everyday life is the consultation and on-going relationship chronic illness suffers have with medical professionals.

Medications are objects that have a functional purpose to improve a person's health, mediate symptoms and ward off ill health. One's associated understandings, situations and identity all contribute towards understandings of medications. When chronic illness is experienced it can change performances, plans, meanings and self perception, which formerly contributed to one's identity. For people with chronic illness, medications function as a mediator of ill health, as opposed to warding off ill health or improving health. Chronic illness will still be present with or without the medication; however the use of medication may reduce symptoms.

The following chapter will discuss the research design, participant recruitment, data collection methods and data analysis methods that were used to explore what medications mean to Māori households.

CHAPTER TWO: METHODOLOGY

Medications are a fundamental technology for treatment in health care, and a substantial component of health care cost in this country (PHARMAC, 2008). Exploring what medications mean to people and how these objects are used within everyday life provides information that can inform strategies for enhancing the safety and efficacy of medication use. This research utilises a broad ethnographic approach (Griffin & Bengry-Howell, 2007) to capture the complexities and fluidity of popular understandings and medication use in daily life. It investigates understandings and practices around medications within Māori households containing people living with chronic illnesses. Multiple methods were used, including group discussions with household members, individual interviews, household mapping and photographic and diary elicitation tasks. The research was informed by the notion that households are a therapeutic space for the care and maintenance of health, and constitute a significant place for medication storage and use in everyday life. My study is important because Māori are disproportionate users of the health system, experience health inequalities, and have the poorest health status of any ethnic group in New Zealand (King & Turia, 2002).

This chapter provides rationale for my focus on specifically Māori households with members living with chronic illness. Following this, I provide an overview of the recruitment processes used and the characteristics of the four households that participated. Section three then explores the four phases of my engagement with the households and the specific research methods used. The chapter concludes with an explanation of analysis process used, namely my approach to the analysis was based on an inter-disciplinarily method that brought together analytical strategies necessary for the needs of the specific research. This approach corresponded well with the messiness of everyday life and the complexities of medication practices in domestic settings.

Why focus on the use of medications to address chronic illnesses in Māori households?

Despite medication being a common object in many homes, there has been no research that has examined the spatial and material practices involved in the everyday use of medications within Māori households. Such a focus is significant because homes provide a spatial context that is related to personal identity, security, privacy, respite and care (Mallett, 2004). People experience a sense of control and freedom in the home, in which everyday routines and practices, including the use of medications, are enabled and enacted (Dupuis & Thorns, 1996). The home is thus a particularly important social and psychological space (Easthope, 2004; Saunders & Williams, 1988), providing a locale that fuses the “physical unit of the house” and the “social unit of the household” (Saunders & Williams, 1988, p. 83). The household represents the particular mode of social organisation that is distinctive to a particular home (Saunders & Williams, 1988). Further, medications and their associated understandings are substantially implicated in the care practices that occur, and identities that are forged, within the home. Much of this relates to self-care and self-medication, contributing to the contemporary transformation of the home into a ‘therapeutic landscape’ (Gesler & Kearns, 2002; Williams, 2002). The interpersonal interactions and the placement of bodies and objects in domestic spaces serves to reconstruct the home as a setting for care giving that is also influenced by external professional knowledge, policies and practices (Dyck et al., 2005; Gleeson & Kearns, 2001).

Chronic illnesses are the leading cause of preventable morbidity and mortality, and are an important factor in unequal health outcomes in New Zealand (Ministry of Health, 2010). People with chronic illness are significant users of medications, with this group consuming 70% of national health expenditure (New Zealand National Advisory Committee on Health Disability, 2007). Issues such as compliance, risk and identity involving medications are highly relevant in this context (Hugtenburg, Blom, & Kisoensingh, 2006). Households containing a person with a

chronic illness, therefore, provide a site where medication use will be frequent, important, and, given the nature of chronic illnesses, will potentially involve other household members. These households also constitute a therapeutic place of care where the meanings of medications and their use are highly salient.

'Medications' can be loosely defined as 'things that keep us well', including anything that is ingested, injected, inhaled, inserted or applied. In Churchill Livingstone's Dictionary of Nursing (Brooker, 2002) medication is defined as:

[a] therapeutic substance, taken orally or administered by injection subcutaneously [under the skin] intramuscularly [into a muscle], intravenously [injected into a vein]; also by inhalation [breathing in], sublingually [under the tongue], rectally [inserted into the rectum], topically [on the skin] or transdermally [in the form of a patch worn on the skin] (p. 56).

For this research the term 'medication' is used to describe objects, materials and devices used to manage or mediate symptoms of illness, to ward off ill health, and to cure ailments. Medications include prescription medicines, over-the-counter-medicines, dietary supplements, and alternative medicines including home remedies, rongoā Māori and other cultural remedies. Medications that are not included in the research are any illegal drugs or substances.

Participant recruitment and household profiles

The participants for this research came from four Māori families living in Hamilton, Aotearoa New Zealand. Each household contained at least one adult or child with a diagnosed chronic illness. Such households provided sites where medication use was likely to be frequent, important, and involve other household members. Households were broadly defined as an individual's residence or a collection of people living together in the same place. To maintain the privacy and confidentiality of the families involved, each household and their individual members were given pseudonyms. Each household has been "named" after native plants that have rongoā Māori properties: Kōwhai, Pūriri, Harakeke, and Pōhutukawa.

Prior to participant recruitment an ethics application for the research was submitted to The University of Waikato's Psychology Research and Ethics Committee and approved on the 20th May 2009. Recruitment of participants began in early April 2009 and was completed in late June 2009. I began my recruitment process by approaching individuals about the study (as opposed to approaching the whānau as a collective). This targeted approach allowed me to fully explain the study and process of data collection to one member of the household, enabling that member to approach their whānau and contact me if they wanted to participate in the research. It was important to approach recruitment in this way in order to eliminate any difficulty or fear whānau may have perceived about the complexity of this research. This enabled me to create a space, when data collection commenced, in which participants felt confident and comfortable in sharing their views and perspectives. Prospective participants were recruited through known local contacts, connected socially or professionally, who passed on the 'General Information Sheet' (see appendix A), to a household. A household member then contacted the researcher to express interest, ask questions and engage in the research process. This recruitment method, known as 'snowballing', was helpful as it enabled participants to be approached through known contacts whom they trusted (Biernacki & Waldorf, 1981; Penrod, Preston, Cain, & Starks, 2003). Trust was vitally important, as the project required the researcher to enter into participants' homes to talk about personal health matters.

Data collection was conducted over a three-week period. A total of eleven people participated in this study. Of those, ten identified as Māori and one person identified as Pākehā. Seven participants were women and four were men, households comprised of ages ranging from two years to 78 years. A diverse range of occupations were represented. Characteristics of each household such as location, medication regimes, and medication use are described in detail below. The amount of information on the chronic illness(s), condition(s) and medication(s) the householders used reflects the amount of information the household shared with the researcher and whether or not they knew the names of the medication.

Harakeke Household

The Harakeke household is located in east Hamilton, in a low socio-economic area (New Zealand Parliament, 2006). Harakeke house is not related in any way to any of the other households in the study. The house is a small two-bedroom home with one bathroom. The household is comprised of three members, two adults and one child. Kahu is a 26-year-old unemployed Māori male who lives with his partner Megan and their child, Sarah. Megan is a 25-year-old Pākehā female who is currently studying at university. Sarah is two years old and attends a local crèche.

In the Harakeke household, both Kahu and Megan very rarely take medication. They generally consider themselves healthy and perceive medication as unnecessary unless they become severely ill. Sarah is the main user of medications. In particular, she uses medicated creams every day and often consumes prescription antibiotics. When Sarah was one year old, she developed chronic atopic eczema. The eczema is a generic condition, which she may have all her life and currently cannot be cured. Symptoms, however, can be reduced, with medication or topical creams. At times, Sarah's eczema gets infected and has to be treated with a long-term (3-6 months) antibiotic, Fluoxicillin Sodium. Sarah has also been prescribed a topical cream, Glycerine cetomacrogol, to help temporarily relieve the itching. This needs to be administered 10 times a day and requires Sarah to be totally undressed and coated with cream from head to toe.

Pōhutukawa Household

Pōhutukawa house was located in East Hamilton, also in a low socio-economic area (New Zealand Parliament, 2006). The house is a one story, three-bedroom home with one bathroom. The house is comprised of two adults, who occasionally have mokopuna stay. John is a 63-year-old Chinese-Māori male who lives with his wife Rachael. John works for the local council. Rachael is a 60-year-old Māori female and is a nurse. Rachael did not participate directly in this study, but is mentioned frequently by John.

In the Pōhutukawa household, John and Rachael have their own medication regime, ranging from taking around eight to 16 pills a day and two injections. Both John and Rachael have chronic illnesses and perceive their medications necessary for maintaining their health and daily functioning. John has been taking prescription medications for over 10 years, as he has Type II Diabetes and regularly injects insulin into his abdomen. John has a prescription for 20 units of Insulin, Glipizide and Metformin medication for his diabetes. He also takes Accuretic medication for his blood pressure and uses home remedies such as manuka honey and aloe vera for other ailments. John has a number of tasks he needs to perform to monitor and maintain his blood glucose levels. Tasks involve regular monitoring of blood glucose levels with reagent strips and a drop of blood from a finger prick; and a strict dietary plan with specific types and amounts of food and a number of insulin injections, usually once or twice a day, with complex dosage adjustments when needed. John drinks Pepsi Max¹ as part of his diet to maintain his blood glucose levels.

John advises that Rachael has consumed prescription medications for the past eight years and takes Accuretic medication, daily, for her blood pressure. She also takes two other forms of medication, which John was unable to name.

Pūriri Household

The Pūriri household is located in North Hamilton, in a medium socio-economic area. The house is a two story, five-bedroom home with two bathrooms and the household is comprised of three adults and two teenagers. Tui is a 78-year-old Māori male who lives with his son Tāne, Tane's wife Erin and their two children. Tāne is a 47-year-old Māori male and is a computer scientist. His wife Erin is a 44-year-old Māori female and is an academic auditor. Teowaina is a 15-year-old Māori female who attends high school. Their son did not participate in the research.

¹Pepsi Max is a low-calorie, sugar-free cola, marketed by PepsiCo as an alternative to regular Pepsi and Diet Pepsi (Pepsi-Cola Company, 2010).

In the Pūriri household, each adult has their own medication regime, ranging from taking around eight to 16 pills a day. Three household members (not including Miriama) have several chronic illnesses and all perceive their medications as a necessity to stay alive and maintain their health. Tui has had two heart attacks and a ruptured ulcer that nearly turned gangrenous. He also has high blood pressure. He has been on long-term medication for four years. Tui takes an array of medication, which include Aspirin, Digoxin, Furosemide, Benazepril medication. He also wears a compression sock and has a Beclazone asthma inhaler. Tāne has sleep apnoea and has to use a Continuous Positive Airway Pressure (CPAP) machine to help him sleep at night. He also has high blood pressure and heart problems. He has been on long-term medication for two and half years. Tāne takes a number of medications including Aspirin, Digoxin, Diuril, Furosemide, Metformin and Mirtazapine. Erin also has sleep apnoea and uses a CPAP machine. She has recently come out of hospital after a wound in her leg became infected. She has high blood pressure and heart problems. Erin has been on long-term medication for the past three years. Erin takes a number of medications including Aspirin, Bumetanide, Digoxin, Diuril, Indapamide, Metformin and Moduretic. Teowaina was not taking any medication at the time of the data collection.

Kōwhai Household

The Kōwhai household is located in North Hamilton, in a high socioeconomic area. The house is a two story, five-bedroom home with three bathrooms. This household is comprised of three female adults and one cat. Miriama is a 74-year-old Māori female who lives with her daughter Lana, and Lana's partner, Noi. Lana is a 45-year-old Māori female, and is an academic. Noi is a 60-year-old Māori female, and is also an academic.

The Kōwhai household is closely related to the Pūriri household as Lana and Tāne are siblings. In addition, Miriama and Tui are husband and wife and Miriama will often spend time at Tāne's house. When Miriama is

staying at the Pūriri household, Tāne administers her medication and performs related care giving tasks.

In the Kōwhai household, each whānau member had their own medication regime, ranging from taking around one to 24 pills per day. Two household members have multiple chronic illnesses and both perceived their medications as a necessity to stay well and preserve their state of health.

Miriama has been on long-term medication for over 10 years and has survived through a number of life threatening illness, attacks and procedures. These include two strokes; stroke induced epilepsy; mastectomy; a gall bladder operation; an on-going fibrillating heart condition; and thyroid difficulties. The adverse effects of these conditions have resulted in Miriama having several chronic illnesses and conditions. These include dysphasia, which affects Miriama's ability to articulate words and memory recall, fluid retention, semi-incontinence, deafness and decreased mobility. Miriama has also become susceptible to chronic urinary tract infections. Miriama takes a number of medications including Digoxin, Furosemide, Levothyroxine, Omeprazole, Nitrofurantoin, Phenytoin Sodium, Potassium Chloride, Sodium valproate, Simvastatin Sodium, and Warfarin. She also takes a cranberry pill once a day to help prevent urinary tract infections.

Noi has been taking prescription medications consistently for over 10 years and has a number of chronic illnesses, which include asthma, hay fever, gastric complications, Hepatitis C (HCV), and rheumatoid arthritis. Noi is also a cervical cancer survivor. Noi regularly takes Symbicort inhaler twice a day and will take Prednisone in extreme conditions. She regularly uses a peak flow meter to monitor her asthma. Noi takes complementary herbs for her HCV. She also takes a number of medications daily for her gastric problems including Ferrograd C, complementary herbs and calcium.

Lana has been taking medications for the past two years. She currently takes Benzodiazepine daily to help with depression, anxiety and sleep.

Medications are not only limited to the adults in the household, the cat Pango is on Levothyroxine medication for a thyroid condition. He also had a stroke eight months ago and was taking Warfarin medication at the time of the initial household discussion. He has recently developed arthritis in the spine and is currently on painkillers.

Research design for engaging with the four households

The project used a multi-layered and multi-method approach to data collection and analysis. The intent of this broadly ethnographic approach is to acquire a rich and deep set of relevant materials that will provide insights into the complexities of understandings and practices around medications (Griffin & Bengry-Howell, 2007). The advantage of my approach is that it can function with flexibility and use diverse data collection methods (Gray, 2003; Holland & Leander, 2004). Data collection assembled a variety of forms of data, including group discussions, individual interviews, photographs, diaries, household maps, and material objects relevant to medication.

A difficulty with this study was that participant understandings and use of medications can become so routinised to the point of being enacted rather than readily represented. The use of exercises requiring participants to draw floor plans [household map] and photograph objects provided a way of rupturing the taken-for-granted and produced a representation that could be discussed, and used to open up experiences of medications. In a sense, these exercises comprised a kind of breaching experiment in the ethnomethodological sense (Garfinkel, 1967), which renders the unnoticed noticeable and aspects of medication placement and use intelligible. Specific processes for the data collection and justifications for the methods involved are outlined in turn below.

Data collection was organised into four phases within each household that included digital-recorded group discussions with household members, observations, mapping, photographic and diary elicitation projects. In *phase 1*, a meeting was held with a member of the selected household to

introduce the person to the research process, this enabled them to then go away and discuss the information with their household. Once the household agreed to participate in the research *phase 2* began and an initial meeting was held with members of each household to introduce the research, gain informed consent, and identify key participants for the various forms of data collection within the household. This was followed by a general discussion about medication sources, uses and meanings with householders. As part of this discussion, household members drew a map of the house (household map), indicating where all medications were located. These locations were digitally photographed and referenced to the plan. *Phase 3* involved one member of the household producing a diary record relating to the everyday use of medications and noting any aspects of the medication experience at the end of each day for one week. Where appropriate, another family member produced another diary recording instances in which medications came to their attention from advertisements, billboards, and interactions with others. In practice, these two forms of diary tended to be merged and completed by one person. Diaries provided the focus for personal interviews at the end of the week, where the meaning of entries and noted practices were discussed. *Phase 3* also involved photo-production exercises where a member of the household was given a disposable camera and asked to “photograph the world of medications”. Photographs were developed and used in a photo-production interview with the participant. *Phase 4* involved an exit discussion with the entire household that reviewed the research process; it was viewed as a suggestion rather than a necessity, which resulted in one household participating in the process.

Engagements with the households resulted in a large and complex data set comprised of some five household discussions (introductory and exit), four household maps, eight interviews, six diaries and over 50 photographs. This corpus offered multiple forms of overlapping data, various vantage points on the placement, meaning and everyday practices surrounding the use of medications in domestic settings.

Below I provide more information on the activities conducted with the households during each of the four research phases.

Phase 1: Pre-data collection

Firstly, I met with a householder to explain the research collection process and answer any questions. This discussion involved informing the person of the aims of the project and the data collection process. The householder was given the 'Medications in Everyday Life Information Sheet' (see appendix A) for themselves and additional copies for the family. After this introductory meeting, if the household was willing to participate they made contact with me and arranged a time for an initial household discussion.

Phase 2: Initial household discussion

Phase two consisted of a meeting with household participants for three main purposes, these being, to gain informed consent from the participants, to complete the household mapping exercise and to participate in the household discussion and allocate tasks.

At the beginning of the household discussion, two recording devices were turned on. The participants were thanked for their participation and patience. I revisited the information sheets highlighting the goal of the research, the tasks involved, rights as participants, rights of withdrawal, and the researcher's contact details. I elaborated on each point and gave the participants an opportunity to ask further questions. The participants were taken through the consent process and forms, which once satisfied with the explanations, they then signed.

Two householders were asked to complete the Household Mapping task (for an example of the household mapping exercise, see Figure 2). One participant was asked to draw a simple map of the household, labelling all the rooms. The other participant was asked to photograph all medications (which the participants had consented to photograph) in their respective

locations in the household. I also made it clear to the photographer that capturing the exact or normal location of the medication was very important to the research. The participant doing the photography also checked with the household that all medications were accounted for in the photographic catalogue.

When the drawing of the household map and the photographs were completed, the participant responsible for taking the photographs was asked to mark with an 'X' on the household map, the locations where the photographs were taken and to number the 'X's. For example number 1 recorded next to the 'X' representing the location where photograph one was taken, and the number 2 next to the 'X' where photograph two was taken, and so on. This coding helped locate photographed items (medications) on the household map. The 'Household Mapping' was also used as a tool for the household discussion as participants were able to refer to the photographs and map to explain why medications were placed in those household locations.

The household map was used as a tool to help rupture the taken-for-granted processes that can come with storing medication and the flow of medications; and to identify how the medication arrived, where it was located, who used it, how it was consumed, and if it moved beyond the house. Drawing the household map and referencing the storage and placement places of medication allowed the householder to explore their house through the lens of medication use. This enabled the householders to walk around their house and discover medications, rather than reference them from memory. It also enabled them to think about medications within the household and to focus on and engage the topic.

The term 'household discussion' was used here to describe a session where the household participants and I partook in a conversation about medications, guided by the 'Household Interview Schedule' (see appendix C). Household discussions for each of the four households began by referring to the household map and examining each photo taken of a medication's location. Conversation around the location of medications

identified what and how medications were both used and stored within the household. Furthermore, the 'flow' of each medication through the household was determined. That is, how it arrived, where and why it was located in that specific location, how it was consumed and whether the medication moved beyond the household.

Following the discussion about the photos and the map, I asked each household 'What does the word medications mean to you'? This question allowed for further conversation about the topic of interest. During the discussion about medications, further questions or prompts were added as a result of issues arising from the household discussion. These discussions for each household took on average 60 minutes.

Before the initial household discussion was finished, the householders decided who was going to perform the three tasks over the coming week: *photo elicitation task, medication use diary, and general medication diary*. Each household member were given a specific information sheet about the task they had chosen, providing them with the task instructions, their rights as participants (including the right to withdraw) and the researcher and supervisors contact details.

Part of phase two included providing, or having on hand, materials and tools to help complete the household discussion and 'Household Mapping' exercise. Materials included 'Medications in Everyday Life Information Sheet' (Appendix A); 'Medications in Everyday Life Consent Form' (Appendix B); 'Interview Schedule' for the household discussion² (Appendix C); 'Medication Use Diary Information Sheet' (Appendix D); 'General Medications Diary Information Sheet' (Appendix E); 'Photo Elicitation Information Sheet' (Appendix F); two MP3 recorders; drawing materials to aid the household mapping task (at least five blank sheets of A4 paper, and a pen); a digital camera or disposable camera to take photographs of medication and material objects; and new diaries for each

² Note that this interview schedule did not have fixed questions, but was rather a tool to help guide and prompt the researcher during the household discussion (Breakwell, Hammond, & Fife-Schaw, 2003).

participant conducting the 'Medication Use and General Medications diary' exercise.

The data set for Phase 2 included digital recordings of the discussion; household map with the identified locations of the household medications and photographs of the medications and material objects around the house.

Phase 3: Diaries, photographs and interviews

This phase of the data collection process required one person from the household to take *photographs* of anything about medications; one other person in the household to keep a *Medication Use Diary*; and another member of the household to keep a *General Medication Diary*. It was anticipated that by completing these three tasks, a rich set of data regarding the household's world of medications could be collected. It was not essential, however, that all of the tasks be performed, this depended on how many people were present, who was interested in the tasks. One person could do more than one task if they wanted too and this is what happened for some of the households. Participation in the various data collection tasks was conducted with flexibility and with sensitivity to the specific wishes and capabilities of each household. Therefore, tasks that were performed, varied across households, as they changed and altered their level of participation. Flexibility is one of the advantages afforded by the ethnographic approach of this research (Gray, 2003; Holland & Leander, 2004). In sum, each household, where practicable, provided two specific diary records; a *medication use* and a *general medications* diary.

Medications Use Diary: One household member who was regularly taking medication of any sort was asked to keep a medications use diary. This involved recording for one week, the daily consumption of all types of medication, and noting any aspects of the medication experience at the end of each day. Methods of recording the consumption component of the diary was chosen by the participant and included recording on paper, audio recordings, or typed on their computer. This diary was then used as

the focus for an individual interview at the end of the week, where the meaning of entries and noted practices was discussed.

General Medications Diary: In relation to the general medications diary, another member of the household was asked to keep a one-week medication diary recording any time that medications of any sort come to attention in any way (while watching television, reading magazines, shopping, and so on). This could include medications of all types such as prescription medicines, over-the-counter medicines, alternative medicines, dietary supplements, and health care remedies. At the end of each day, this person selected one encounter and recorded more detail about it. Again, the form of recording for this diary was negotiable to suit the specific participant. At the end of the week, an individual interview was held with the diarist to discuss what was noted, not noted and the meanings of entries.

Diaries comprised an introduced data collection method that enabled participants to actively contribute to both recording and reflecting on their own practices (Milligan, Bingley, & Gatrell, 2005). The diaries augmented individual interview methods, fit well with participatory research approach to everyday life (Johnson & Bytheway, 2001; Milligan et al., 2005), and reveal understandings about taken-for-granted issues in health and illness (Elliot, 1997; Verbrugge, 1980). These diaries also provide “a record of an ever-changing present” (Elliot, 1997, p. 2), that was useful in researching sensitive issues (Meth, 2003) over a short period of time (Ross, Rideout, & Carson, 1994).

Photo elicitation: A third data collection method offered to the household members was the photo elicitation task. One member from the household was asked to take photos over a two-week period, of anything about medications; photos that show us how they see “the world of medications”. These photographs were about any aspect of medications that they wanted to show, as there were no specific expectations about the nature or type of photographs. The photographs were taken either on their own digital camera or they were given a disposable camera. Photographs

were then developed or viewed on a laptop, and used in a photo elicitation interview with the participant. Photo elicitation proved useful in enabling participants to move beyond discussions and the written word and explore medications in everyday life through the lens of a camera.

Photo elicitation techniques are increasingly used in social science research (Mitchell, DeLange, Moletsane, Stuart, & Buthelezi, 2005; Nowell, Berkowitz, Deacon, & Foster-Fishman, 2006; Pink, 2007). They are often located within participatory research approaches (Carlson, Engebretson, & Chamberlain, 2006) as the process enhances participant reflexivity and provides participants with a means to articulate their lives particularly in relation to taken-for-granted everyday events, that can be difficult in conventional interviews (Klitzing, 2004). The photo elicitation task also enabled participants to experience a sense of ownership and enjoyment in the research process (Hodgetts, Hodgetts, & Radley, 2006), and facilitated interactions between myself and participants (Felstead, Jewson, & Walters, 2004). Photo elicitation processes involve more than simply taking photographs. When participants are asked to produce and then talk about their photographs, I was able to ask about the commonplace objects and routines, highlighting what may seem mundane or unimportant to them (Radley & Taylor, 2003). The technique invoked processes of picturing their world (Hodgetts, Chamberlain, & Radley, 2007), where the task of photographing things relevant to the research objectives orientates them to see their world differently, with a focus on things worth picturing. This orientates participants to material aspects of their everyday lives and to relationships that give meaning to places and things (Snell & Hodgetts, 2007). When participants make sense of what they see and experience by picturing, links between personal experiences, local contexts and social practices are invoked and revealed (Harper, 2002).

The materials for Phase 3 included; 'Medication Use Diary Consent Form' (Appendix G); 'General Medications Diary Consent Form' (Appendix H); 'Photo Elicitation Consent Form' (Appendix I); and two MP3 recorders. Data from Phase 3 consisted of: diaries; photographs (that the participant

consented to include); and the recorded discussion about the diaries and photographs.

Phase 4: Exit discussion

The exit discussion provided for a review process where the household had the opportunity to disengage formally from the research process. The discussion was offered to participants as a suggestion, as opposed to requirement. If the participants opted to not engage in the exit discussion there was an informal disengagement from the process where the participants were given the opportunity to ask any further questions and they were thanked for their time. Exit discussion covered and reviewed the processes that occurred within that household, and generally involved an overview of what happened, and what was shown, with the researcher also gathering participant reactions and comments to this. Discussions were audio recorded and treated as a data source and a forum for sharing generic findings with the participants.

Analysis

A particular challenge for the analysis of the diverse data set compiled for this research was how to achieve coherence of interpretation across the various forms of data that preserves the complexities involved. Cohen and colleagues (2001) state that a number of factors should be considered: complexity, given the diversity of interacting processes involved change, given the ongoing changeable nature of these processes and social constructions, given the important role of human understandings and meanings involved. In this section the analysis process is described for the household map and reference photographs, photo elicitation photographs, household discussions, individual interviews and diary entries.

My approach to the analysis is based on the notion of researchers as bricoleurs (Kincheloe, 2005) who operate inter-disciplinarily to bring together analytical strategies necessary for the needs of the specific

research. Here, research is seen as a process involving problem solving and flexibility that is adjusted in response to emerging insights (Kincheloe, 2005). This approach corresponds well with the messiness of everyday life and the complexities of medication practices in domestic settings.

A key feature of the analysis was to unravel meanings invested in taken-for-granted everyday life practices. This required particular attention be paid to mundane actions and events (Sheringham, 2006) and the rendering of the familiar as unfamiliar (Chaney, 2002). Specifically, materials were analysed thematically and interpretatively with respect to social and symbolic aspects of medications in general and personal situations in particular. I accomplished this by focusing on routine, on the incidental events and accumulated moments that make up everyday life and how these link to broader patterns of social relations (de Certeau, 1984; Sheringham, 2006), patterns that are intimately caught up in the meanings and practices surrounding medications in the home. This orientation foregrounds the dialogical nature of the analyses, moving from detailed engagements with the home space, daily situations, material objects, personal experiences and practices to broader socio-structural contexts and patterns that frame and constitute them (Lefebvre & Nicholson-Smith, 2007). On the one hand, I unpacked participants' understandings of medications and their use embedded in daily practices and on the other, I conceptualised the social significance of these local instances for the meanings and practices of medications in society today.

More specifically, I employed techniques commonly associated with thematic analysis. Thematic analysis is the process of identifying, analysing and highlighting patterns (themes) within the data (Boyatzis, 1998; Braun & Clarke, 2006). Braun and Clarke (2006, p. 3) write that it "minimally organises and describes your data set in rich detail". The researcher plays an integral role in this process as ultimately they make decisions based on their experience and knowledge of the topic (Braun & Clarke, 2006). This approach allows the researcher to make sense and meaning of the participants experiences and, in turn, the ways the broader social context impinges on those meanings. Using thematic analysis as a

framework allowed me to draw on content, rhetorical, discursive and narrative analytical techniques as required (Braun & Clarke, 2006; Yanchar, Gantt, & Clay, 2005).

The household map was used as a tool to document the storage spaces of medications within the household. During the analysis process the map was used as a reference tool. Matching the photographs with the map enabled me to remember placement and storage areas of the medications and cross-reference the areas in the home with the transcribed material from the household discussion and individual interviews. The photographs were also used as tools to help further interpret participants' accounts of where they placed, stored and used specific medications and how relationships of care were played out in the household. The photographs were also analysed according to their content. A photo table was developed to help assess what was present in the pictures (see appendix J for an example). A grid was completed, for each photograph taken, providing an overall view of who was presented in the photographs, the places they were taken and the objects present. This allowed the photographs to be viewed through a different lens, as they were more than tools for discussion, as their material content was also important.

After analysing the household map and photographs the household discussions and individual interviews were transcribed verbatim. I read over the transcripts and diary entries numerous times, enabling me to become familiar with the participants' accounts. While reading the data set I noted down, on one side of the margin, information deemed to be significant from what the participants said (Braun & Clarke, 2006). Some of the comments were attempts at summarising a response, using one word. Then on a separate document, the comments were extracted and connections were developed between them. Particular subjects, ideas or practices were placed under an umbrella term (theme) that could be recognised as the 'same type'. During this process, I also extracted passages (extracts) that best represented the theme, enabling me not to lose meaning from what the participants said. Each passage or extract was coded with what household it was from, what interview it was and the

page number (for example H1.I2.p3). These processes involved a cyclical progression of reading literature, re-reading the transcripts and diary entries, listening to the recordings, discussing the topic with supervisors and project team members while also re-examining the themes or sub themes in context with other sections (Braun & Clarke, 2006; Bryman, 2004).

Eventually the lists of themes (topics) were narrowed down to eleven main findings. Most of the findings emerged from the core research questions, which had developed from the research aims and previous literature research (Braun & Clarke, 2006). Research questions include, What do medications mean to you and your household? What do you do with your medications? How do medications enter into your home? Where do you store your medications? What material objects in the home are related to medication use? Do you follow your medication prescription instructions? How do you feel about taking medication?

Once an overall finding was developed, the extracted passages from the transcripts were placed under each finding with the corresponding codes. I tabulated this data to see what findings were represented across the households as illustrated in Table 2:

Table 2.

Research findings

Findings	Harakeke household	Pōhutukawa Household	Pūriri Household	Kōwhai Household
Storage	✓	✓	✓	✓
Accessibility of medication	✓	✓	✓	✓
Ineffective medication	✓	✓		
Valued pursuits		✓	✓	✓
Approach to medication	✓	✓	✓	✓
Relationships with med. Prof.		✓		✓
Forgetting to take medication		✓	✓	
Effective medication			✓	✓
Effect on daily life	✓	✓	✓	✓
Resources that help			✓	✓
Lay knowledge	✓	✓	✓	✓

In the above table, a tick was given if the finding was discussed or alluded to in each household. Although most findings were present in each household, the findings shown in grey dominated more of the discussion in that particular household. It was also vital that the finding was a dominant discussion point across all the data sets (discussion, individual interviews, diaries and photo elicitation tasks) in that particular household and there was a number of extracts that were able to demonstrate the prevalence of the finding. This process provided the structure for the following findings chapter, where eleven thematic areas are documented and interpreted in relation to each household. Each household will exemplify a subset of the eleven themes; the first three households will present three themes in the context of the household and the remaining household will present two themes.

CHAPTER THREE: FINDINGS

As described in the previous chapter, I identified eleven emergent themes that link with the research aims. The themes were evident across all four households. Some householders, however, discussed some themes more than others. For this reason, and to reflect the complexity and fluidity of social meanings medications take on in the lives of householders, I decided to narrate the presentation of my findings through each of the four households in relation to their knowledge of medications, what it meant to take medication, the social practices around the use and storage of medications and how medications are accessed and distributed.

The sections that follow draw on each of the four households to illustrate two or three selected themes as they are reflected on in the lives of participants and in the context of the households.

Harakeke Household

This section presents the findings from the Harakeke household. Firstly, definitions of the three key themes from the Harakeke household are discussed. Following this, the findings are presented and examined, including extracts from the household discussions, individual interviews and diaries. Lastly, a summary is provided outlining the key concepts covered in the section.

The themes that emerged from the Harakeke household are presented below, followed by a broad exploration of the theme in relation to its links with the meanings and understandings participants ascribed to their medications.

- (i) *Storage*: exploring how and where householders stored their medications and when and where they administered medications gave insight into the consumption and social practices associated with medication use. The functionality of medication related to where the medication was stored

therefore, influencing the householder's usage patterns and reflected the associated values and meanings that were given to the objects.

- (ii) *Accessibility of medication:* The costs associated with seeing medical professionals and obtaining prescriptions, over-the-counter medication and alternative medications often reflected the extent to which medications were perceived of as necessary, accessible or otherwise. Accessibility of medications often influenced how participants treated medications, the extent to which inaccessibility disrupted daily life routines, and whether participants felt they could do without their medications.
- (iii) *Ineffective medications:* How participants perceived their medication's effectiveness influenced their usage patterns and reflects the associated value to the user. What medications mean to householders can be explored through householders' interpretations of how medications work and their perceived effective or ineffective outcomes.

Theme One: Storage

Across all households, medications were stored in a multiplicity of places. It was common practice to store medications in places of convenience, as the householders liked having them in spaces where they were ingested, applied, inserted or injected. Medications were stored where the householders could visibly see their medications; they became visual reminders around the home, specifically the kitchen and the bedroom as medications were taken around meal times, first thing in the morning and last thing at night. The Harakeke household was the only household where a young child resided. The other households had children (mokopuna) visit and stay from time to time, but they were not in permanent residence, therefore, discussions around child safety were less of a focus.

Where medications were stored in the Harakeke household are shown in the household map below (Figure 1). This map was drawn by Megan, and

the numbers on the map refer to where medications were stored. These numbers also correspond to the photographs that were taken.

The bird's eye view of the household map outlines where all the medications were located across the space of the household. Most of the medications were stored in the kitchen, followed by the living room. The bedroom and bathroom also contained medications. Although medications were found throughout the house, they were placed in positions of convenience or in accordance with storage directions, such as Sarah's liquid antibiotics being stored in the fridge.

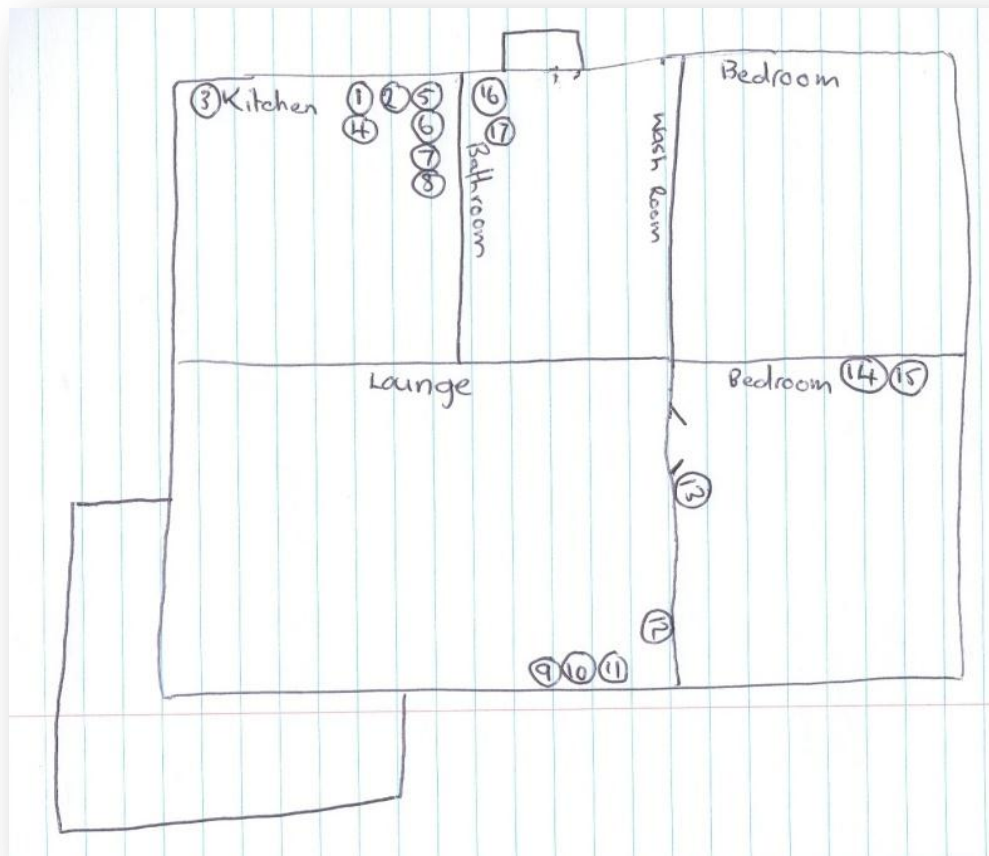


Figure 1. Harakeke household map.

The Harakeke household stored their medication in places of convenience. Even if Sarah was able to reach and touch the medications, they were not placed in safer places as Megan believed that Sarah was able to learn not to touch the medications. The main medication storage spaces were in the kitchen and the living room. Megan also stored

Panadol and cough lozenges that she acquired from her family, in her handbag. Other medications were stored in the kitchen fridge, above the fridge, on the microwave, kitchen pantry, kitchen cupboards, bathroom cupboards, bathroom draws, bedroom vanities, bedroom draws and the bedroom wardrobe. Although a number of storage places are described, there were not a lot of medications stored in these areas. There were only 32 medication items found in the house (as opposed to hundreds found in the other three households). The majority of these items were Sarah's medicated creams and antibiotics, and Megan's dietary supplements.

Medications in the household were stored close to where it was most often used. Most of Sarah's creams were placed on the bookshelf (shown in Figures 3 & 4), close to where Megan changed Sarah's nappy or dressed her. During the photo-referencing task, however, Sarah's medicated cream was also found in the bathroom on top of the toilet, (shown in Figure 2) demonstrating that medications are mobile within the space of the household and able to be found in multiple locations. For example, where they were last administered, consumed and/or applied.



Figure 2. Sarah's medicated cream's placed in the bathroom, on top of the toilet

Kahu and Megan discussed how at times Sarah could reach the medicated creams in the bookshelf. Megan explained that Sarah was not able to open the containers but has managed to open the tubes of cream and has tasted the contents. Megan explained that she monitors Sarah

most of the time, however there have been occasions where Kahu was asked to watch her and she has touched and ingested medications. When Sarah does touch the creams she is disciplined by Megan. Megan then places the creams back to the exact same place (which was within reach and sight) so that she learns that she can look but not touch. Megan said that after a while Sarah lost interest in the items and did not bother to touch them, until, of course, a new medication came along. Megan: *“Like, sometimes if we get a new tube, aye, and if it’s the new stuff she gets more curious with but her other ones she’s quite happy just leaving them”*.



Figure 3. Sarah’s medicated cream’s in the middle of the bookshelf, in the living room.



Figure 4. Sarah's medicated cream's in the bottom of the bookshelf, in the living room.

As shown in the photographs, Sarah's medication creams and tubes were stored with other household items such as books, photo albums, photo frames, CDs, baby wipes and Sarah's soft toys. They are also within reach of Sarah but have become commonplace objects that Sarah sees and plays around in her daily life.

During the process of taking photographs and referencing them to the household map, Kahu and Megan recognised all the old and expired medication that they had accumulated. Megan explained that they usually store medication until the contents are all gone. The medication is kept and stored because it comes in handy the next time they become unwell. Megan: *"They [antibiotics] stayed around for a while and then I got sick one time and I ended up taking them. Because I was, like, "Oh, I've got some antibiotics, that's right." I can't remember what I took it for but, yeah, I took it and then I was sweet."* Megan explained that she only takes her antibiotics until she feels better, then she will keep the remaining medication for future use, although she is unsure what the medication is specifically prescribed for. Both Megan and Kahu explained that they use medications in this way to fully utilise it for their own ends.

Medications were stored in a number of areas around the Harakeke home. The householders utilised and relied on features of their physical

environment such as using the bookcase for storing medications and daily routines to help them organise and store their medications. For instance, the top of the toilet was used as a temporary storage area for Sarah's medicated creams as Megan's activities of that particular day saw her apply Sarah's cream in the bathroom. These daily routines were ever changing and occasioned during the day. Medications were stored and used in accordance with their functional purpose, which exceeded the need to store medications out-of-reach from Sarah. Therefore, medications became commonplace objects, where they had become 'part of the furniture', which was an intentional practice by the householders. The introduction of medications in the Harakeke home has supplemented its function as a site for care, a place where Megan cares for her daughter placing medications in viable storage areas, which propagates the notion that medications become objects of care and the spaces of the home are reflected as care sites.

Theme Two: Accessibility of medication

Of all households, the Harakeke household was the only one where the adults did not have a chronic illness. Medications presented less of a focal point in their data set. Their daughter Sarah, however, did have a chronic illness and access, storage, use and effectiveness of her medications were topics of discussion. Throughout the conversations with the household it was clear that cost was a dominant factor in the decisions and access options they made. When accessibility of medications was discussed among the other households they focused more on their 'relationships with medical professionals' and their 'approach to medications' (these themes are explored further in the Pōhutukawa and Kōwhai households).

The Harakeke household discussed how they obtained their medication through family, friends, pharmacies and supermarkets. Megan talked about how she has received over-the-counter medication and supplements from her Mum and Nan because she was not able to afford the products herself. Throughout the discussions with the household, it

was clear that cost influenced when Kahu and Megan visited the GP, used medications and accessed specialists.

The cost of GP visits and medication was often the reason for choosing not to go to the doctors or to use prescription or over-the-counter medication. Kahu and Megan often felt they did not have enough money to pay for the doctor's appointment and the medication. As a result Megan and Kahu rarely took medications. Medications were, therefore understood as a product that was helpful when unwell, but were not a necessity in the context of their symptoms and daily life. In New Zealand, cost plays a major factor in the decisions people make to go and see a doctor (Jatrana, Crampton, & Norris, 2010). A recent study by the University of Otago, found that Māori and Pacific peoples are particularly affected by cost barriers when trying to access medication, and are less likely to attain prescription items because of the cost (Jatrana et al., 2010). Contributing factors include poverty, family structure and individuals having multiple health problems. Research by Jatrana and Crampton's (2009) research illustrates that cost remains a reason for not accessing primary health care or attaining a prescription in New Zealand.

Self-diagnosis was an important process when deciding whether or not to visit a doctor. Megan discussed how she would self-diagnose her own illnesses and if she thought her sickness was 'viral' then she would not visit the doctor. Megan believed that if her illness was caused by a viral infection then the doctor would simply tell her that there was no cure and that she did not need to take any medication. Megan also avoided seeing her doctor, and the associated cost of the visit, by simply ringing and asking for a repeat prescription when she could. Nabalamba and Wayne (2007) examined the decision process of individuals who decide to seek medical attention. The likelihood of seeking medical attention was related to the persons association with need. Where patients would 'self-perceive' their condition and those with chronic conditions were more likely to seek medical attention. Other factors that stopped people from seeking medical help included cost, no time, no one to supervise the children, fearfulness

and embarrassment. For Megan the reason to seek medical help needed to be legitimised such to as attain medication.

Kahu discussed how he did not like going to the doctor; as a result, he does not use or obtain prescription medications. He explained that he does not like spending money on going to the doctor and then paying for prescription medication. Kahu explained that he does not buy any medication over-the-counter because it costs too much and has become accustomed to not using medication when he is unwell. When he does use medication, it is usually Megan's antibiotics that she had not finished taking.

Kahu: Yeah, I never go to the doctors.

Facilitator: Because does it cost you.

Kahu: Yeah. And even if it was \$5.00 I still wouldn't go. I just don't see why I should.

Megan: And the doctor where he goes – he signed up with that free one – but it's always a long wait.

Kahu: Yeah, I don't like it.

Megan: And so the last couple of times when he was going to go he's been waiting and then he's been, like, "No, I don't want to go, let's go home."... And he won't wait. So, he won't pay and he won't wait! So, we don't go.

Even when the cost factor is removed Kahu still does not access the doctor. Kahu believes that his practices around medication usage and access are influenced by growing up in a low-income family where they were unable to visit the doctor or afford medication. So he has become accustomed to not using medication and just using home remedies, such as taking lemon drinks when he has a sore throat. It is important to acknowledge that Māori men are disproportionately represented in New Zealand as having the poorest health status in terms of disease and mortality (Willams et al., 2003).

An epidemiological study on Māori men's perception and experiences of seeking medical help for prostate problems in New Zealand found, the barriers to health seeking behaviours were related to inadequate access to culturally safe and appropriate health care for Māori (Willams et al., 2003). Health seeking behaviours are thought to be determined by social and cultural expectations of what constitutes normal pain and illness, "ethnic

groups with consistently poor health status will accept pain and symptoms ... as a normal part of life, rather than seek treat[ment]” (Willams et al., 2003, p. 72). These factors may contribute towards health seeking behaviours in the Harakeke household. During the conversation with Kahu it was apparent that medications for Kahu were understood as complementary items in the household. That is, he will not go out of his way to attain them however, if they are in the house, he will use them if illness symptoms persist.

Megan and Kahu both avoid trying to spend money unnecessarily on doctor’s visits and medications. With their daughter Sarah having a chronic illness, however, they do not hesitate to take her to the doctors to get advice on her illness. When Sarah was diagnosed with chronic eczema Megan’s Nan advised her to take Sarah to a specialist. Megan had not considered taking Sarah to a specialist. Megan explained that if her doctor had suggested it, Sarah would have been placed on the public waiting list and it would have taken at least a year to get an appointment. Her Nan, however, offered to cover the cost of seeing a specialist privately. While cost played a factor in Sarah accessing the specialist, this was not an option that Megan would have even entertained, had it not been suggested by her Nan.

For the Harakeke household access to medication was based on cost, time and necessity, these factors were influenced by the social context in which medications were accessed and distributed to the public. The household overcame the expense of medications by gaining access to them through family and by basing access decisions on the necessity of the health situation and avoiding unnecessary doctor’s visits. In the Harakeke household medication access is a complex process embedded in a social and cultural context that is debatably influenced by cost (Jatrana & Crampton, 2009; Jatrana et al., 2010; Willams et al., 2003; Zola, 1973), these cost factors may have contributed to the perception and process in which medications were accessed and understood.

Theme Three: Ineffective medication

Medical technology and advancements are evolving rapidly (Warden Carroll, 1998). In many cases there are medical ways of alleviating or at least managing ailments. The effectiveness of medication, however, can vary from person-to-person (Warden Carroll, 1998). All households experienced different degrees of medications being ineffective, including having negative side-effects, slightly reducing symptoms or not reducing them at all, being difficult to use or apply and stopping individuals from doing certain activities. Various reasons were given as to why medications were considered ineffective. For example, the medication not being taken as prescribed, because they forgot to take it or it was too hard to fit into their lifestyle and/or there was a communication break down with their doctor resulting in their prescription not being suitable. In the Harakeke household, Kahu and Megan felt their daughter's medication was ineffective because it only slightly reduced the symptoms of atopic chronic eczema and found the creams difficult to use and apply as directed by the physician.

Megan discussed how she originally took Sarah to the doctor where she was diagnosed with eczema. The doctor advised her to apply medicated creams over the infected area 10 times a day to prevent Sarah's skin from drying and cracking. After a period, the medication did not help and Megan explored other avenues of treatment suggested by her family and friends. She tried alternative medication and dietary changes for a short time but they did not improve Sarah's eczema.

The medicated creams that were prescribed did not appear to reduce the severity of Sarah's symptoms. The cream did not make a difference to her rash spots. It spread the eczema around her body. The eczema was now at a stage where it covered her entire body except her face. Although Sarah's parents felt the medication worsened her illness, they also felt they had no other alternative but to continue using the medicated creams, because without it, Sarah's skin would dry and crack predisposing her skin to bleeding and at times, infection. Sarah's GP and specialist had offered no other solutions.

Megan: They said it was eczema. And it wasn't like the type of eczema that I had seen before. You know, I thought eczema was different than that but they said it was eczema.

Kahu: It was like almost after we started the cream it started coming on bad, aye?

Megan: The reverse after that.

Kahu: It sort of helped it along.

Megan: Spread it ... something like that. It got worse after we started putting it on.

Facilitator: Do you still use it [the medication]?

Megan: Yeah, because otherwise it's even worse.

Kahu: Yeah, it just gets bad. It gets dried out.

During the interview Megan described how she administered Sarah's eczema cream on a daily basis and gave her medication. Megan's Nan then recommended and paid for Sarah to see a specialist, who diagnosed atopic eczema and prescribed antibiotics for Sarah. Both parents described how Sarah's condition was very difficult to manage, as there is no cure for her illness and the medication only slightly reduced her symptoms. In the extract below, Kahu and Megan explain how Sarah's eczema developed and the treatments they used:

Kahu: So it sort of just came out of nowhere [eczema]. Because it just started looking like rashes first thing and then turned into eczema.

Megan: She just got it all over her body but not on her face and then they [doctor] just gave us creams, like, to rub in, like the aqueous cream. And then it just kept getting worse and worse and so we kept taking her back to the doctor and then they gave us these other Locoid creams to put on as well. And but it's all just pretty much like managing it. It's not going to get rid of it.

Throughout the interview and the medication use diary and photo elicitation tasks, both Megan and Kahu talked about how they felt helpless when Sarah was in pain. They felt the medication had 'let them down', in that it was not at all effective and that it appeared to have actually contributed to the spreading of the eczema. As Sarah's eczema was consistently itchy, she scratched her skin continuously, the worst times being when she could not sleep due to the irritation. Kahu: *"and those ones were just sick looking aye [her eczema rashes]? Like her singlet and her t-shirt was just blooded out on one whole side".*

During the interview, Megan described how she found it difficult to administer Sarah's cream ten times a day and only manages three applications. She described how the task is very monotonous and draining as Sarah has a tantrum each time she has to put the cream on. Megan explained that Sarah would keep still for Kahu when he places the cream on her, but he rarely administers the cream. Megan described how she finds the cream disgusting as it has a 'gross' smell and it sticks to Sarah's clothes and makes them greasy, with this also deterring her from applying the cream more than three times a day.

Megan and Kahu's accounts regarding Sarah's medications being ineffective invoke a cyclical process in which the behaviours, perceptions and decisions feed into each other. They proposed that the cream initially spread her eczema and only reduced her symptoms. Megan applies the cream 30% of the time. This in turn reduces the effectiveness of the cream and contributes to the creams not being used as prescribed (which reduces its effectiveness). This contributes to their perception that the creams do not work. The cycle begins again with Megan only applying the creams three times a day as opposed to the recommended ten. This experience is also presented in the Viswanathan and Lambert (2005) study where participants experienced different degrees of medications being effective, some participants found their medications to be very effective while others reported they took their medication on a regular basis but found the medication to not be effective. They explained, however, that they regularly 'forgot' their medication. The study concluded that medication effectiveness was interrelated with the belief in medications effectiveness and regular medication use.

Household summary

Briefly, patterns of medication use in the Harakeke household reflected their understandings of the efficacy of medication. Kahu and Megan avoid using medical services for themselves because of the perceived expense and lack of service. Although Kahu and Megan tried to avoid using medical services, their attitude with respect to their daughter was different.

While they prioritise medical treatment for Sarah, how her eczema has developed, the organic nature of the disease, the perceived lack of efficacy of the medication to reduce symptoms, and the fact that there is no cure, does not encourage them to persist with medication as prescribed. A cyclical decline to a helpless situation appears to have result, with Kahu and Sarah feeling powerless to improve life for Sarah and themselves. In the context of the Harakeke household medications are expensive and for this reason not used as directed. They are accessed under-conditions that for Kahu reduce his dignity and contribute to him 'not being bothered'. With respect to their daughter Sarah, medications have very little meaning when they are perceived to present limited or no hope for an improved future, as well as significantly disrupting household routines because of the intense energy required to administer them.

Pōhutukawa Household

This section presents the findings from the Pōhutukawa household. Firstly, definitions of the main themes from the Pōhutukawa household are discussed in this section. Findings are then presented in the context of the Pōhutukawa household, including extracts from the household discussions, individual interviews and diaries. Lastly, a summary section reviews the key concepts covered in the section.

The themes that emerged from the Pōhutukawa household are presented below followed by a broad exploration of the theme and its links with the meanings and understandings participants ascribed to their medications.

- (i) *Valued pursuits*: Understanding the value participant's place on their responsibilities, life goals and ambitions: such as meeting social responsibilities, work commitments and whānau well-being, provides insight into the decision-making processes of using, administering and prioritising medications in their daily life. Furthermore, it provides an important perspective on

explaining the variations in medication practices between the households.

- (ii) *Approach to medication:* How medications are integrated into daily activities and household flows reflect household and participant's understandings of their medications. For example, whether medications are readily accepted, reluctantly accepted or resisted, in turn revealing the effects medications have on their day-to-day decisions and lifestyle. These understandings and meanings of medication are an important part of explaining the variations in medication practices.
- (iii) *Relationships with medical professionals:* The relationships participants had with medical professionals often reflected prescription practices and the extent to which medications were perceived of as necessary, accessible or otherwise. This often influenced how participants treated medications, the extent to which inaccessibility disrupted daily life routines, and whether participants felt they could do without their medications.

Theme Four: Valued pursuits

Many households' juggled jobs, relationships and other responsibilities, meaning that, at times, their own healthcare needs came last. Charmz (1991) acknowledged that when people are placed in positions where they have to compromise their valued pursuits, such as wanting to maintain work responsibilities or upholding family obligations, people place pursuits first, subsequently compromise their illness management and sacrificing their health condition. Charmaz (2006) acknowledged that medications have to be able to fit into people's lives, not the other way around. People with chronic illnesses, however, often had to make compromises in some way to fit medications into their lifestyle.

In the Pōhutukawa household, John found that his valued pursuits were more important than managing his health so he could live longer. He explained that he would rather continue to meet his social and work commitments and integrate his medications in his lifestyle than comply

with his prescribed regime and in his words *“live a less active and productive life”*. John discussed how he has a very busy lifestyle. He works fulltime, is a full time student and has additional responsibilities that require regularly travelling long distances. On average, John has 16-18 hour days where he can be working, studying and travelling. John maintains that he has not changed his lifestyle and that his medications fit into his life, not the other way around.

John explained that he would continue to maintain his lifestyle and medication practices even though he is aware of the potential negative health consequences. John explained that he utilises his medications to benefit him and his lifestyle and made it clear that his priorities in his life are his study, work and family life, with medication priorities fitting around these.

John: Our goal is to preserve Māori land to get it in the best condition so that it will become an asset for future generations. So if I want to achieve [this] goal I need to be able to work long hours, do full time work so I need to utilise medications to be able give me the energy to do these things which goes against the prescription where I have to take my medications at certain times.

Facilitator: So you can't get the quality of life that you want if you used your medications as they prescribe them?

John: When I'm looking at Pākehā ways of looking at things they want to preserve your health first ... regardless if other aspects in your life suffer, so that means take meds at a certain time each day but that doesn't fit in with me.

John's main goal is to look after and preserve Māori land for future generations. John feels that he needs to maintain his current lifestyle, where he has the freedom and flexibility with his medications, in order to reach his goals. John feels that the 'Pākehā way' of taking medications does not give him enough flexibility and would take over his life and interfere with his focus. To John, medications are malleable in their use as he is able to utilise the medications to maintain his current responsibilities and activities in his life. For example, John has learnt when he injects his insulin it can give him a surge of energy within 30 minutes. He utilises that energy to keep him awake if he needs to drive, *“I was at the beach today and I got really really tired. So I did the injection, I*

waited about five or 10 minutes ... So I sort of gear up again. So I know that I don't have to keep up with the regimen every day I just use it when I really need some energy." 'Self managing' medication and 'self tailoring' medication is becoming more apparent in compliance literature where participants are seen to modify their regimens by taking them strategically or symptomatically, or adjusting the dosage amount to avoid adverse effects or make the medication regime more tolerable (Elliott, Ross-Degnan, Adams, Safran, & Soumerai, 2007; Ingersoll & Cohen, 2008; Pound et al., 2005). This was apparent in John's case, as he would take his medication in a self-recognised strategic manner, allowing him to go about his daily activities, whereas without the medication, he was unable to maintain his energy levels.

Gaining insight into John's life ambitions and goals is an important part of comprehending the complexities of his everyday life in which he uses and understands medications. John recognises that the way he utilises his medications is not recommended practice from medical professionals. John's valued pursuits, however, such as preserving his ancestral land, which involves a lot of travel around the country may be more important than the long-term consequences of his illness management. In order to fully comprehend John's experiences in his everyday life with his medications is more complex than identifying his life's goals and valued pursuits.

Leventhal, Brissette, and Leventhal (2003) explained that patient beliefs around the cause, consequences and controllability of diabetes and understandings of their medications are the core drivers when patients make decisions about whether or not to take medicines and under what circumstances. Through John's experience with education services, he has learnt the consequences of uncontrolled diabetes such as blindness, kidney failure, increased risk of heart disease and painful peripheral nerve damage (Gaster, 2008). John strives to avoid such outcomes, by not following prescribed regimens and advice from his doctors and educators, and admits that he would rather, *"go out with a bang and achieve my goals"*. Therefore accepting a greater likelihood that he will have a sudden

death. This impression of John facing a sudden death is based on John's own personal opinion.

John: I have this strategy. If I continue misusing my medications and not following recommendations, there's a high probability I might have a sudden death. So I don't want a quality of life where I'm so debilitated, where someone will look after me. That's not a positive way I want to look at my life I want to be able to live my life and not be bogged down with following this and that. I know I don't have much flexibility with my medications but I use all the flexibility I want!.

John discussed how he takes his medication based on how he feels rather than the prescribed administration. He feels that, although his prescription does not allow for much flexibility, he can consume his insulin when he feels his body needs it. In John's narration, he made it clear that he wants to maintain his lifestyle and quality of life at any cost. He views compliance with medications leading him down a path of debilitation where he will live a longer, but not better, life.

Simmons, Weblemoe, Voyle, and Prichard (1998) explored 'personal barriers to diabetes care' and suggest that the greatest personal barrier is when perceived benefits of self-care are outweighed by the perceived disadvantages. John perceives the self-management of his diabetes as being functional and adaptable to his lifestyle and priorities in his life. He believes that his medication management works well for him because he has an awareness of what his body needs and when he needs time to rest. His approach to medication usage, however, is not the recommended practice by medical professionals as he is not maintaining regular insulin levels and testing. Simmons and colleagues (1998) state that the benefits of sustaining diabetes are less likely to be appreciated by those diagnosed if the symptoms are not apparent or severe, do not require medication, have less knowledge of the potential harm and have experienced dissatisfaction with past care provider. John has experienced a number of the above factors and finds the benefits of adhering to a specific diet and medication regime; do not outweigh the benefits of maintaining his valued pursuits because he has not experienced any immediate and apparent effects from his medication-taking behaviour.

Theme Five: Approach to medication

Chronic illness can affect people in many different ways physically, mentally and emotionally (Pound et al., 2005). Literature illustrates that people who have chronic illnesses act in a certain way towards their illness. They can have emotional reactions such as, depression, anxiety, a 'why me' state of mind and can question their identity in terms of no longer being considered a healthy person (Carrick et al., 2004; Cohen et al., 2001; Doran, Robertson, & Henry, 2005; Herek et al., 1990; Scott & Arslanian-Engoren, 2005; Whyte et al., 2002). Every individual within the households presented a different approach to medications whether they readily accepted them in their life, accepted their medications reluctantly, or, resisted taking their medicines. Pound's (2005) research on resisting medications identified all these factors.

In the Pōhutukawa household, John is, in many ways, very independent when it comes to managing his diabetes. Through many conversations and disagreements with his wife, they have learnt as a couple to let each other deal with their own health issues, as they do not share the same views. John: *"over the years she's getting use to me, but does not necessarily mean she agrees with me"*. John explained that as a nurse Rachael believes in the bio-medical model of practice, where you follow your doctors and diabetes educators' advice and take medication strictly as prescribed. John feels differently, *"as a nurse she's been brought up on the Pākehā medical model and what I'm talking about does not fit in to that. Therefore she gets hōhā because I'm a lay person talking about all these other things that's not likened to normal medical [model]"*. John takes his medication when he feels his body needs it and only tests his blood sugar levels every three months. John believes that if he routinely stays fit, eats a proper diet and feels energetic then he rarely needs to test his blood sugar levels. John was asked if he was confident in his approach to keeping himself well. He replied *"it has nothing to do with confidence, this is my life and that's what I am living."* Therefore, John believes his approach to medication management and use is about self-

agency and self-determination, whereby he manages his diabetes and does not let the regime rule his lifestyle.

As well as sharing different health management views, John described how he and his wife stored their medications in different places and took responsibility for the taking of their respective medication. Where John previously stored his medication reflected his wife's requests, as she preferred all their daily medication to be stored in a certain kitchen cupboard on the third shelf. When John stored his medications in the cupboard, however, he would regularly forget to take his medication. So they compromised and John now stores his medication in his study, where Rachael rarely goes.

Facilitator: The study's right next to the kitchen so I guess what I'm wanting to sort of discover is the relevance of having the pills in the in-tray when obviously you've got to take the pills with food so there must be some kind of routine that you go through that allows you to go past your in tray?

John: Oh, yes. This is the routine: my in tray is in the office. Rachael doesn't want to see me have my medication anywhere so I've actually come to the in-tray, a place where it doesn't seem to annoy her... she's really quite tidy and the problem is I live in the house too, and I'll make it untidy! So I actually need to move in different areas that I'm, she knows I've got to take tablets that have to be somewhere so it's found a home there that tends to be compatible with both of us.

In this narrative, John explains that his wife prefers medications to be out-of-sight because it creates clutter and mess. They have both compromised, however, and although John has to make a trip to his study to get his medications this is adequate, as he seems to remember to take his medications when they are stored in his in-tray. Therefore, the storage of the medications has to do with their personal dispositions as opposed to safety or other variables. De la Cuesta (2005) research discussed how caregivers of dementia relatives 'create spaces' in order to gain more therapeutic areas in their home, and how these spaces function as environments that support and enable care. In the Pōhutukawa household, the functioning space of the office is transformed into John's therapeutic space for taking his medication, a space that permits the

storage and administration of his medication and allows other spaces in the house to remain for family life.

The management and adaption of chronic illness at home can create stress, as it requires adaption by the individual and family members (Newby, 1996). Newby (1996) discusses how family responses to chronic illness vary according to severity, disability and coping mechanisms of the individual. In the Pōhutukawa household, it is no different. As a couple both John and Rachael have adapted to one another's requests around the storage of medications, where medication is taken and they have had to compromise when they did not share the same point of view. During conversations with John, however, he made it clear that he was not going to compromise when he took his medications and the dosage amount, *"I'm the one that's more responsible than anyone else about taking medications and ultimately I'm the one that is affected, so I will use my medications the best way I see fit."* John's approach to taking his medications could be his way of coping with his chronic illness, with the stress of managing his medications, juggling his responsibilities and maintaining his relationships.

While John's approach to chronic illness management can be perceived as the 'man alone' in terms of care and support from his whānau, for John it is about his own self determination; the ability to make his own choices in terms of his own life and self agency where he can retain his control. Self-care for John is not without the impacts of his relationships with his whānau and household, as his home is the care context in which his medications are used and stored. The nature of that care, medications and associated medication materials are clearly negotiated with his wife. These negotiations contribute to the peace and balance in the household.

Theme Six: Relationships with medical professionals

People's relationships with their doctors, educators and specialists were discussed across all the households. The Harakeke, Pōhutukawa and Pūriri households felt their doctors were only a part of a process in gaining medications. They felt that the doctors and specialists too quickly

prescribed medications and felt that they were rushed out the door, rather than assessing their health, finding solutions, providing them with alternative options and explaining the effects of the medications they intended to prescribe. Several studies have indicated that increasing the involvement of the patient in their own treatment outcomes creates acceptability, satisfaction and compliance with prescribed treatment (Kane, 2001; Lambert & Naber, 2004; Peuskens, 2004).

Diabetes education can be defined as “an exchange of knowledge, tools, and practices that will address the client’s needs” (Ellis et al., 2004, p. 1). This broad definition can encompass different educational approaches such as group and individual learning sessions. In the Pōhutukawa household, John received education from individual consultations with a diabetic educator and his GP. The relationship with doctors and diabetes educators dominated many of the discussions about medications with John. He talked about how GPs and diabetes educators provided very little practical information on the management of diabetes and the support provided was minimal and hard to attain.

During the interview, John related how, when he was first diagnosed with diabetes, the information he received from his GP was poor and not very informative. John also felt that he did not know what kind of questions to ask because he had little understanding about diabetes and was not sure if anyone in his family had been diagnosed with it, “*I don’t have the right questions to ask and they’re not going to tell me*”. He later found out that his sister, mother, grandmother and cousins all have/had diabetes. Since his diagnosis, he received further education from diabetes educators, however, he felt the information was not practical and the way they presented the information was not appropriate. In the extract below, John explained how the diabetes educators used scare tactics to draw diabetics into using their medication as prescribed.

John: You listen to the education and they tell you how you're going to die, like, chop your arms off, legs off, go blind and all those things. And they seem to do the crazy thing about trying to scare you into something. And more so, when they tend to do that, that's an old routine of what I've been brought up [with] before, I end up not listening to them. So I [don't] take too much notice of that information.

John explained that diabetes educators focus on negative outcomes that can occur when a person's diabetes becomes progressively worse. John believes that diabetes education needs to be presented positively, with situations where people are able to maintain a good level of health. Simmons, Weblemoe, Voyle, and Prichard (1998) conducted a study on the barriers to diabetic care in South Auckland and found that the effectiveness of diabetic education was interrelated with many of the barriers to diabetic care. Participants in the study felt that the education they received lacked practicality in that they could not see the advice transferring into their lifestyles and community. They also found it hard to talk to their diabetic educators as they felt intimidated or had communication issues, as they needed help with translation (Simmons et al., 1998). John feels the education he has received on diabetes plays on fear, fear of what can happen if you do not follow the medication, exercise and diet regimen. This has led him to not communicate with his educator and GP honestly about his medication practices. Therefore, John's understandings around medication usage and storage mainly come from his own personal experience. As a result of this displacement with medical professionals, John understands that his medications are his own to interpret and utilise the best way he sees fit.

John receives his prescriptions from his GP every six months and before the prescription is given, he needs to have a check-up. John finds it difficult, however, to schedule an appointment with his GP as they are both busy and are rarely available at a mutually agreeable time. John has been advised by his GP to take time off work to make the necessary appointment, however he feels that this is not an appropriate answer to accessibility issues and that taking time off work is unnecessary. As he

finds his GP's advice inadequate, he chooses to monitor his own condition in his own way.

John: Doctors and educators think we have unlimited sick leave just to see them to answer question. Often their answers are pathetic and they carry no responsibility for the cost to the clientele ... Just lately, I've tried to see my doctor but she's been too busy. They said Wednesday, Thursday. I said, "Oh, I'm busy." She wants to see me more than I want to see her so I will just leave it until she panics! As long as she reorders my medication, it doesn't bother me because they're not really in a position to monitor me properly.

In the extract above, John explains that he feels that his GP is not in a position to monitor his diabetes effectively; therefore, he relies on his own "instincts" to manage his illness. He feels that there is probably a lot of useful information about diabetes, but he feels he cannot access it through his GP and diabetes educators. He is therefore, selective about what information he uses and proceeds to draw on his own personal experiences such as working out how to benefit from taking medication at a certain time in the day. John is also selective when it comes to sharing information with his GP about the way he uses his medication. He feels that because she is not a specialist she would not understand, *"Oh, no. My doctor is a general practitioner and I would get hōhā explaining how I use my medications to her"*.

Wilson, Hutchinson, and Holzemer (2002) study discussed a similar practice as John described, where participants 'self tailored' their medication regimen by relying on three strategies; body listening, gauging, and negotiating. This involves listening to how their body felt rather than administering medications at a regular time; gauging, involved making comparisons and estimates about the severity of their conditions and negotiating with health professionals about medication options and having input into determining what medications they used. John described situations where he would listen to his body and gauge the severity of his condition, however he never felt comfortable discussing the truth about his medication use to any medical professionals. Therefore, medications become a very personal and private practice where John is the main decision maker when it comes to caring for his chronic condition.

Professionals and diabetes care providers consider diabetes education as a pivotal component of diabetes treatment (Ockleford et al., 2008; Wheeler, Wylie-Rosett, & Pichert, 2001). John viewed his experience with diabetes educators and his GP as negative and their advice to be impractical. This created barriers in communication, where questions were not being fully understood (or even asked) and inadequate answers were provided. Access was also a problem for John as he was required to see his GP on a regular basis, however he felt this process was unnecessary because the appointments were not required as he managed his own chronic illness without the help of his GP. Subsequently, John's relationship with medical professionals leads to experimentation with his medication, non-compliance with his prescribed medication regime and self-management of his diabetes. Ultimately, John views his medications as tools, which provide him with the means to achieve his lifestyle demands, while living with a chronic condition. This aspiration to live a 'normal life' and meet the social demands of daily living is one of the key aspirations for people living with diabetes (Ockleford et al., 2008).

Household summary

In summary, the Pōhutukawa household is comprised of a married couple with each partner taking responsibility for their own health needs. John fits medications into his life in ways that are convenient to him, rather than as prescribed. He 'listens' to his body, taking note of tiredness, signs of being unwell and malaise. Contrary to the views of his frustrated wife who is a nurse and who has withdrawn from giving him any advice about his health care, John adjusts his medication according to how he is feeling or to permit other activities like eating and driving. John finds solace in his aspirations to reach his life's goals before he passes away and uses this account to explain his approach to medication usage and administration. John explains that although his approach may seem like an unpractical way of managing his health he would rather 'go out with a bang' than endure a long drawn out illness. John also feels that because he has not experienced any severe consequences of using his medications in this way he believes that because he is not "critical", a situation where his

organs could fail and his mobility be reduced, he does not need to change his current practice.

Pūriri Household

This section presents the findings from the Pūriri household. Firstly, the definitions of the three key themes from the Pūriri household are discussed. Following this, the findings are presented and examined including extracts from the household discussions, individual interviews and diaries. Lastly, a summary is provided outlining the key concepts covered in the section.

The themes that emerged from the Pūriri household are presented below followed by a broad exploration of the theme in relation to its links with the meanings and understandings participants ascribed to their medications.

- (i) *Forgetting to take medication:* not taking medication or not taking it as prescribed could have implications for whole households, not just for one individual. Forgetting to take medications could disrupt household relationships revealing the significance that medications play within social relationships and householder roles.
- (ii) *Effective medication:* How participants perceived their medication's effectiveness influenced their usage patterns and reflects the associated value to the user. What medications mean to householders can be explored through householders' interpretations of how medications work and their perceived effective or ineffective outcomes.
- (iii) *Effect on daily life:* How medications are integrated into daily activities and household flows reflect household and participants' 'attitudes' towards their medications. For example, whether medications are readily accepted, reluctantly accepted or resisted, in turn revealing the effects medications have on their day-to-day decisions and lifestyle. These understandings

and meanings of medication are an important part of explaining the variations in medication practices.

Theme Seven: Forgetting to take medication

In every household, members at some time forgot to take their medication. The reasons behind failing to remember to take medications varied between individuals, for example, routines were not followed, medications were not accessible, memory loss, stress and, in some cases, individuals did not believe in the efficacy of their medication so they did not strive to remember. Some of these reasons were reflected in the Pound and colleagues (2005) study that found that participants struggled to remember to take their medications as routines were not in place or not used, they had an underlying belief that taking the medication caused short and long-term harm. The adverse effects of not taking one's medication varied between the householders as some relied heavily on medication to manage their illness, and, for others, the adverse effects were not immediately apparent. The consequences of not taking medication also related to how much medication was not taken and over what time period.

In the Pūriri household, four members had chronic illnesses and relied heavily on medication to keep them alive. Medication-taking practices were integrated into their every day routines. These routines enabled them to remember to take their medication and for some, reminded them to administer others medication. Routines are an essential part of managing medication regimes especially those who take long term medications, as they provide a way to integrate and minimise the efforts of taking medication (Gamble, Fitzsimons, Lynes, & Heaney, 2007; Sidat, Fairley, & Grierson, 2007). Regular medication-taking resulted in the medication being perceived to make a difference. Taking medication on a regular basis, however, was sometimes felt to be enervating, especially when considering the householders busy lifestyles.

In the Pūriri household Tāne administers his father Tui's medication in the morning and evening. At times, however, he finds it difficult to get his father to take his pills, as Tui will regularly, and in Tāne view purposefully,

forget them, even though they are right in front of him. In the extract below, Tāne discusses how he goes to great lengths to get his father to take his medication, which usually involves him placing the medication in front of him at meal times.

Tāne: Dad has a bad habit, if you put meds in front of him and he won't even take it when it's right there. You know, and you say, because it goes hand in hand with breakfast or lunch or whatever it is. So he can have breakfast and you say, "There's your porridge and here's your meds"... and I come back ten minutes later when he's finished and he's wandered off and the meds are still there and the porridge is eaten up. So I pick them [up] and get a cup of water, take it down to his room and he'll be at his office or whatever sitting at the desk and I say, "Here, you go, you didn't take your meds." So I put it there and come back twelve o'clock or something and they're all still sitting there ... you've just got to keep chasing [him].

For Tui the perceived forgetfulness of taking his medication may be linked to the fact that he does not like taking medications, as he believes that once you start to take medications on a regular basis the medications will affect your immune system and cause it to become weak. Therefore, when Tāne places the medications in front of Tui more factors may be interplaying than the perceived forgetfulness of Tui. Also, while Tāne is focusing on getting his father, and mother when she comes to visit, to take their medications, he can forget to take his own medication, compromising his own medication regime and placing his health at risk. Looking after others can sometimes affect one's own self-care as sacrifices are made to fulfil care giving responsibilities (Boland & Sims, 1996; Read & Wuest, 2007) which include failing to take one's own personal medications. In the case of all the households, one main carer looked after other household members needs. Having one primary caregiver who takes full responsibility for care is very common (Burton-Jones, 1995; Johnson, 1983; Nygaard, 1991; Parsons, 1997) and if the main carer becomes unwell, it can affect the caring structure in the home. Therefore, the application of medications is very important in balancing health, lifestyle and relationships in the Pūriri household.

Although medications were taken routinely on a daily basis, interviews with the Pūriri household, indicated that the taking of their medication was not a

rigid task. They felt that a certain amount of flexibility around when to take medication was necessary as it enabled them to feel a bit more in control over their daily routine. This supports what is found in the chronic illness literature, where people with chronic illness have explored ways of simplifying their regimes, such as adjusting pill-taking times, reducing the dosage amount or even discontinuing the medication (Adams et al., 1997; Charmaz, 2002; Ockleford et al., 2008; Shoemaker & Ramalho de Oliveira, 2008). In other words, they took on more and more control and responsibility with their own medication management. In the following extract Tāne describes the household's medication routine.

Tāne: You know when you're in the hospital and they come round every day at the same time as breakfast and then they come round with the meds, the doctors always come at a certain time. That would be so controlling of your life, it gives you no flexibility. Whereas the way that we're taking them at the moment I'd think we're reasonably flexible. We're not so rigid and you have to take it within sixty seconds of this time or else you're going to self destruct or something. We associate the taking of meds with meals and so if we have a late breakfast then the meds are going to be late. If we have early breakfast, early meds.

The household's daily routine involved taking medication with meals, as it fitted in with the prescribed times of morning, midday and afternoon. Their regime became complicated when medication is to be taken at a set time before food. Because meal times are not the same time each day, the time to take medication can vary on a daily basis. Tāne explained that they simply avoid taking this medication and ask the doctor for another alternative. Requesting medication changes is not always expressed to the doctor as many patients simply discontinue the medication (Charmaz, 2002; Haslbeck & Schaeffer, 2009; Shoemaker & Ramalho de Oliveira, 2008). In Tāne's case he explained that he felt he had a good relationship with the GP and also knew from past experiences that alternative medication options were available. For the Pūriri household medication management is an important part of their everyday life. By understanding their daily practices with medications we learn that their medications are a necessary part of their life, where compromises and flexibility are just as essential.

Forgetting to take medication can have severe adverse effects especially when you have several chronic illnesses that require medication. In the Pūriri household four householders had a chronic illness(es) and relied on a number of medications to keep them alive and maintain their current state of health. In the extract below, Tāne explains an instance when his father, who at the time was living alone, repeatedly forgot to take his medication, causing his health to deteriorate and the wound on his leg to become infected.

Tāne: ... [a]nd if you went to have a look at the box you would see there's like about twenty blister packs and not one of them had been touched ... it cause[d] other complications for him [as] he got a wound on his leg and normally his meds would've assisted with the healing of it but because he wasn't taking his meds he spent three months with the wound and [in] the care of the District Nurse. It ended up turning kind of gangrenous, he had to go into hospital for an operation which they cut part of it out and he spent the next eight months getting it fixed up...but then he moved here and spent from December to now getting it right and it's only just come right and that's a direct consequence of not taking his meds.

Tāne's recounting of Tui's lack of compliance and resultant infection illustrates the meanings Tāne associates with his father's medications. They are life giving, infection avoiding and a way to keep hospital admissions and medical professionals out of their lives. As a result, Tui's leg will never be the same and he now has to wear a compression sock for the rest of his life. His leg also has to be elevated at night to help the fluid circulate out of his leg. Forgetting to take medication has had drastic results and now Tāne has developed for Tui, procedures and lifestyle changes that he needs to maintain to stay healthy.

For Tāne, while extremely frustrating and sometimes stressful, reminding Tui to take his medication, to raise his leg and assist his father with his compression socks, are 'small' health steps towards avoiding more serious and disruptive consequences. These care giving strategies have not been well documented in the literature as the main findings focus on the burden of care, such as feelings of loneliness and isolation, physical demands and financial costs (Boland & Sims, 1996; Burton-Jones, 1995; Johnson, 1983; Kramer, 1997; Nygaard, 1991; Parsons, 1997; Read & Wuest, 2007; Scott

& Arslanian-Engoren, 2005). De la Cuesta (2005) who explored the experiences of Colombian family caregivers caring for relatives with dementia, identified the 'craft of care' where caregivers use inventive strategies and evolve their lifestyles to restore health. Like Tāne, the caregivers in the study take vigilant care of small ailments and conditions to avoid illnesses and conditions worsening. Medications play a vital role in the actions of care giving as they are objects that can represent aroha, hope and give the carer a way to provide a means of healing.

Forgetting to take medication can be the result of change in daily routine or current routines being ineffective, however it can reflect a person's attitude towards their medications, specifically the underlying belief that the medications are also doing them harm (Haslbeck & Schaeffer, 2009; Shoemaker & Ramalho de Oliveira, 2008). It is not possible to fully comprehend and consider every element which leads a person to forgetting their medication, however the consequence of it affects the social relationships and householder roles (de la Cuesta, 2005; Shoemaker & Ramalho de Oliveira, 2008), reinforces that medications are important to the well-being and harmony of the household for the Pūriri household.

Theme Eight: Effective medication

All households discussed how they viewed the efficacy of their medication. Both the Harakeke and Pōhutukawa households had issues with their medications not being effective in their use, biomedical outcomes, and manageability. The Pūriri and Kōwhai household found their medications were effective and had a positive influence on their health and household. Efficacy was related to the medication being compatible with the user's body in which they experienced very little or no adverse effects, the prescription instructions fitting in with their individual lifestyles, and the medication being easily accessible and affordable. Therefore, efficacy was due to a number of factors which was not solely related to the biomedical outcomes, such as reducing fluid levels in the body (Webster, Douglas, & Lewis, 2009). Research on patient compliance found that the

effectiveness of the medications contributed significantly towards the patient's compliance to their medication regimen (Gordon et al., 2007; Shoemaker & Ramalho de Oliveira, 2008; Sidat et al., 2007; Urquhart, 1994; World Health Organisation, 2003).

In the Pūriri household, members viewed their medication as mainly having a positive effect on their lives. Tāne, Erin and Tui maintained a level of health through a daily medication regime to manage their chronic illnesses. Their medication enabled them to sleep, keep their blood pressure down, heal their wounds, maintain organ function, and continue to be mobile. Tāne, Erin and Tui made it clear that they would not be able to function, or even live that long, without their medication. Even though they have a high reliance on medications, however, at times they did forget to take their medication.

For the Pūriri household, they believed that for their medication to be effective they had to take their medication daily. When Tui was living on his own in town, he became ill because he was not taking his medication regularly. His whānau then decided it was safer for him to move in with them so they could monitor his medication-taking practices and overall health. Due mainly to Tāne's monitoring of his father's illness and administration of his medication, Tui has maintained his level of health and has not been admitted to hospital since he moved in with them.

Tāne: He was actually living in town by himself for about two years and he only moved here in December last year. And he wasn't really keeping up with his meds by himself. We'd go home and find whole boxes of blister packs that he hadn't touched type of thing ... his health has improved since he's been here. And, yeah, it's more about routine. Once you get into a routine or when the meds need to be taken then we tend to be on track.

During the household discussions, Tui expressed that he did not like taking his medication; and when he was living on his own he often forgot to take it, which resulted in him having to be hospitalised. The functionality of spaces within the home become increasingly significant when people become chronically ill, "social and geographical worlds shrink through constrained mobility and chronic illness" (Dyck et al., 2005).

Therefore the management of chronic illness becomes difficult to maintain if home spaces, practices and relationships do not support the management of chronic illness (Dyck et al., 2005). Once Tui moved into a home space that supported the management of his chronic illness he was better equipped to meet the regime demands of his medication. As a consequence, Tui began to take his medication on a regular basis with the help of his son, and began to regain his health. As a result, his medications were perceived differently due to his recent experience of maintaining his health.

For the chronic illness householders, taking medication is a matter of life and death. They rely heavily on the medication and subsequently their medications become their insurance to keeping them alive. During the household discussion Tāne outlined how long each member would survive without medications.

Tāne: If Mum goes a day without her meds [there is] a very serious chance she'll have a seizure and a stroke and end up in hospital. Dad, he can go a couple of days without his meds and he's still fine. Me, I'm gasping for air if I'm out of meds for half a day type of thing.

Tāne's narration highlights the awareness he has on his whānau mortality without medications. Medications provide stability and give the users a sense of control. Medications are viewed as 'lifesaving' and this perception was shared across studies with participants who have hypertension (Viswanathan & Lambert, 2005), asthma (Adams et al., 1997), epilepsy (Conrad, 1985), and diabetes (Ockleford et al., 2008). Subsequently, people with co-morbidities and complications are more likely to endorse medications as being 'lifesaving' (Viswanathan & Lambert, 2005). For the Pūriri household, they understand medications as being vitally important, medications mean that they can maintain a certain level of health, and while their medications are not without side-effects, they are willing to accept these as a trade-off (Shoemaker & Ramalho de Oliveira, 2008).

Tāne, Tui and Erin described how they took an array of medications but did not specifically know what each medication pill was prescribed for. For

them knowing the specific name for the medication or its functions was not important, as long as the medication was effective and the side-effects were not too severe. In the extract below, Tāne discussed how he did not know what all his medications were prescribed for. Despite this, he trusted that the medications were effective and necessary, viewing his medication regime as having a very positive effect on his life.

Tāne: Yeah, but for some unknown reason some pills that I take I haven't got a clue what they are ... and yet the doctor says it will do me good ... what I [do] know is that without them my health deteriorates rapidly in days and I go from being reasonably ok to hardly able to breathe and feel like my heart's about to stop at any second.

Tāne's narration discusses how his doctor views the medications as 'good,' therefore encourages him to take his medication. This encouragement, coupled with the immediate effects if he does not take his medication, contributes to his compliance with his medications. Field, Ziebland, McPherson, and Lehman's (2006) study on heart failure patients understanding of medications, shared a similar view, describing how participants did not know the name of the pill they were taking but recognised it was important because of the recommendation by their GP and the medications effectiveness. Due to the progressive nature of chronic conditions, however, treatment options and medications that work one day can vary the next day. Therefore, effectiveness of medications and patients compliance should be viewed on a "dose-to-dose basis [where] the decision to adhere is made each day, dose by dose" (Wilson et al., 2002, p. 12). For the Pūriri household, each day they take their medications to avoid severe health outcomes: their medications enable them to breath, stabilise their heart rate, and circulate fluid around their body and so on. How they perceive their medications effectiveness to maintain these bodily functions influences their usage patterns and reflects their associated values to the user.

The Pūriri household members discussed how medications were a necessity for them to stay well. Without their daily medication regime Tāne, Erin and Tui's health deteriorates rapidly, therefore, when they take

their medication daily their health is maintained. Although the medications are effective in improving certain aspects of their health, it does not solve all ailments, illness, or is not without adverse effects (Webster et al., 2009; Wilson et al., 2002). The effectiveness of medication is not a fixed perception as health conditions, environmental factors, relationships and social practices change, alter and transform (Armstrong, 2005; Conrad, 1985; Dowell & Hudson, 1997; Sidat et al., 2007; Urquhart, 1994; Webster et al., 2009; Wilson et al., 2002; World Health Organisation, 2003). For the Pūriri household, they believed that their medications were effective and had a positive influence in their life, and this was reflected in their attitude towards their medications and the way they routinely used their medications.

Theme Nine: Effect on daily life

Exploring the participants daily life with medications enables the taken-for-granted world that is usually private and unseen, to be revealed (Coudry, 2003). Medications on some level affect the everyday life of its user, however the significance of its affects are attributed to a number of factors. Factors include prescription regimen, adverse effects, lifestyle, responsibilities and relationships inside and outside of the household (Haslbeck & Schaeffer, 2009). Currently there is very limited knowledge about the multiple mechanisms involved in the effect medication has on ones daily life. Research examining medication usage has mostly focused on older populations, finding them to take many medications concurrently and to be considered as at risk of side-effects, such as confusion and falls (Thomson & Poulton, 2002). These studies and other medication use and misuse research, however, are focused on compliance issues, where users either conform or stray from prescribed regimens (Campbell et al., 1983; Gilbert, Luszcz, & Owen, 1993; Haslbeck & Schaeffer, 2009; Helling et al., 1987).

Across all the households, medications affect daily life differently, according to the individual and relationships involved. In the Harakeke household the application of medicated creams were a huge part of

Megan and Sarah's routine and mother daughter caring relationship. In the Pōhutukawa household, self-care and monitoring were a part of John's daily life with medications. In the Kōwhai household, daily life orientated around Miriama's well-being which involved care from her daughter, while Noi self managed her own medications. The Pūriri households daily life also orientated around care and self-care with medications, with Tāne caring for his father and mother (when she visited), also monitoring his own chronic illnesses, with Erin self managing her own medications.

Within the Pūriri household are four chronically ill members, (including Miriama who transitions between the Pūriri and Kōwhai households), and between them they take a lot of medication. Tāne not only has to monitor his own chronic illnesses, but also manages his father's, and at times, mother's daily care, as well as working from home. A large part of the household's daily life involves the administration and application of medications, attending medical appointments and considering the adverse effects of medications. It was evident that the household's daily life was a balancing act of prioritising needs (for example, having to take medication) against wants (wanting to go places but cannot because of the adverse effects of the medications). In the following section the Pūriri household's daily life with medications will be explored covering how side-effects and the application of medications can disrupt daily life, and how a medication routine is important to maintaining health and upholding responsibilities.

Routine is a very important part of the Pūriri household's daily life.

Routine is described as deliberately "designed behavioural patterns [that are] used to organise and coordinate activities along different axes of time, duration, social and physical contexts, sequence and order" (Haslbeck & Schaeffer, 2009, p. 3). Throughout the interviews the household discussed how Tāne had tailored a daily routine around the administration of medication, the tasks involved with preparing, tending and changing bandages, obtaining medication and making medical appointments. This is reflected in the extract below.

Facilitator: And then you take care of your Dad? ... as in getting the medication, checking when he's going to need the next blister pack ...

Tāne: Run him to the doctor. All those sorts of things.

Facilitator: How do you find that?

Tāne: It's a bit of a headache to get you [talking to Tui] to go to the doctor, get the medication, get the blister packs, make sure you take the meds in the morning, when we just leave it in the egg cup ... and then we've got to top it off with having to put you in the shower, take the bandage off when you have the bandage on, aye? Cream your leg; make sure you're ready for the District Nurse when she was coming.

Caring and tending to these responsibilities takes time, patience and care. Tane discusses his father's medication routine commenting on how he monitors, sources, presents, and pursues his father's compliance and other care needs and his own frustrations. Interesting here is how Tane tells his care story. The story is told through a narrative of a father – son relationship, being told by a son to a father. The interviewer becomes an observer of the conversation even though they are the cause of the exchange. The narrative is a telling of their care relationship, focussed on the substances and behaviours that present ways of being together, of bringing care into their relationship, and of offering care from son to father. While disruptions to daily routines are apparent, sub-routines to respond to disruptions demonstrate an enabling resilience. The story is told in a loving and compassionate way but at the same time invites Tui into a safe space to contradict or elaborate. Switching the focus to telling their story to his father of their relationship suggests a respect in directness and honesty. To do otherwise, is to reveal the intimacies and struggles of their relationship to some other without seeking permission to do so – an act tantamount to diminishing the status of his father in public. Through medications, Tane navigates his cultural obligations to care for Tui's physical and medical needs and cultural status as a father, grandfather, elder, and family head. Reading beyond the medications, illness and frustrations of growing old and becoming dependent, we find a son motivated by the cultural obligation of manaakitanga, of giving due regard to the mana of his father.

In the Pūriri household, family life and medication use are interwoven into the fabric of the household. Medications clearly had an effect on householder's daily lives. For Tāne and Tui, the taking of the "water" tablets (Furosemide) meant that they needed to have ready access to a toilet for the best part of the morning.

Tāne: [Medications] impact on your lifestyle and routine and choices of what you can do during the day ... but in general his meds, like Mum's, the one that wants you to go to the toilet all the time to get rid of fluid [Furosemide]. You build your day around that. Mum takes her meds in the morning for that so we can't charge out anywhere in the morning that is longer than twenty minutes to half an hour from a toilet ... dad is the same although his are like, he's about thirty-forty minutes before he has to go.

The well-being and health of Tāne's parents directly affected his lifestyle. Tāne can no longer leave the house without considering if there are adequate toilet facilities where they were going, which in turn impacts on the activities they can do and how long they can travel for. At times, the adverse effects of taking the medication result in it not being administered until they are back at home, with this impacting on the routine built up in the Pūriri household. Haslbeck and Schaeffer (2009) identified that people with chronic conditions find it particularly challenging to maintain proper medication management in their lives, as they consistently have to alter and revise them. For Tāne, as a medication user himself and carer, medication must be functional enough to manage the side-effects. If the medication results in too much restriction, compromises must be made. Problems and concerns about side-effects of medications have been researched, however these studies tend to focus on physical details of the adverse effects rather than the effect of medications on daily life (Carrick et al., 2004; Rogers et al., 1998). In the Pūriri household, medications are understood as being a necessary to maintain health and the household strives to comply with their medication regime. Medication usage, however, is variable as daily life is complex (Haslbeck & Schaeffer, 2009).

When the household were discussing the effect medications have on their daily life, Tāne spoke about how he has difficulty using his Continuous Positive Airway Pressure (CPAP) machine regularly. He has to use the

machine each night as it assists him with his breathing by helping to oxygenate his blood. As explained, in the extract below however, Tāne does not feel comfortable using the face apparatus and often does not use it. He explained that even though he understands that he needs the machine to help with his breathing, and without it he is at risk of his health deteriorating, Tāne found the machine does not meld with his body enough to become unnoticed, so he is constantly reminded of the ailment. This makes the machine 'uncomfortable' and 'unnatural'.

Tāne: For me ... I feel like it's not assisting me breathing. It's like it's stopping me from breathing ... and they keep telling me to persevere and eventually you'll get used to it but I really can't ... I know all the reasons why I'm meant to be using it and there are definite side-effects to it all and I'm fully aware of it but sometimes it's just, it doesn't feel natural, that's for sure.

Therefore, even though Tāne has been advised by his specialist to use the CPAP machine, and he is fully aware of the health benefits and risks he takes if he does not use the machine, Tāne chooses not to use the machine regularly because it is uncomfortable and affects his personal relationship with his wife. Therefore, if the medication and its administration are not comfortable and manageable, the impacts are too great on the user's daily life and as a result may not be effectively used. People with chronic conditions strive for normalcy and develop strategies to integrate medications into their lives, however these strategies are only effective through the process of 'trial and error', as users evaluate side-effects and the medications usability (Haslbeck & Schaeffer, 2009).

Medications affect the daily lives of the Pūriri household in a number of ways. For Tāne's parents it means taking medications after each meal and experiencing their side-effects, which can restrict activities. For Tāne, taking and administering medications are a part of his daily life, where he has to mould his daily activities to the care needs of his parents. For Erin, medications are a part of her daily routine where each meal is followed by medication. Due to the complexity of daily life and responsibilities that need to be met, the household's routine needs to be flexible and adaptable. However for some householders their medication regime is not

very forgiving. If medications are not taken daily the household structure and routine can become disturbed. Tāne explains the importance of maintaining medication responsibilities: *“one of the primary reasons why you try and keep up with their meds and all their appointments and stuff is because; if they deteriorate in any way I’m the one there to support them afterwards. Believe me; I don’t want to be chasing around after them more than I’m doing at the moment.”* Therefore medications mean that householders can gain a sense of control and certainty in the face of illness (Shoemaker & Ramalho de Oliveira, 2008).

Household summary

The Pūriri household is a multigenerational household where children, parents and grandparents reside. Both parents and grandparents have chronic illnesses and manage their illnesses through self-care and supported care perspectives. Their home provides a spatial context where individuals can experience a sense of control and freedom, where everyday responsibilities, care practices and routines can be enacted (Dupuis & Thorns, 1996). Their daily life involves an array of medications and enables them to create structure when confronted with the chaos that illness brings. Routines were developed to remind and alleviate some of the on-going pressure to meet the demands of the medication regimen, which Haslbeck and Schaeffer (2009) term ‘compliance stress.’ Examples of routine disturbance, such as forgetting to take medications, highlight the important role medications fulfil, physically, emotionally, and socially. When medications are forgotten, an individual’s health can deteriorate rapidly, which in turn can affect their efficacy and create a ripple effect on the whānau, as caring responsibilities increase and routines alter. For the Pūriri household medications are understood as a necessity in their household that supports stability, mobility, healing and health maintenance.

Kōwhai Household

This section presents the findings from the Kōwhai household. Firstly, definitions of the two themes from the Kōwhai household are discussed. Following this, the findings are presented and examined in the context of the Kōwhai household, including extracts from the household discussions, individual interviews and diaries. Lastly, a summary is provided outlining the key concepts covered in the section.

The themes that emerged from the Kōwhai household are presented below followed by a broad exploration of the theme and its links with the meanings and understandings participants ascribed to their medications.

- (i) *Resources that help*: What participants developed, adapted or purchased to optimise their medication-taking practices revealed to me the lengths to which participants went to integrate medications into their households and into their daily lives. Resources included personal health diaries, labelling their own medication and using pill containers to remember and track consumption.
- (ii) *Lay knowledge*: Lay knowledge is acquired through experience, education and emotional comprehension of a phenomenon. By gaining insight into the householder's lay knowledge of medications, we can begin to understand what medications mean to the respective households.

Theme Ten: Resources that help

Each household had their own unique routines and practices around taking medications. Some individuals relied on the emplacement of the medications to invoke reminders, some relied on other householders to remind them, and others were handed their medication on a daily basis by a loved one. Other household members developed and adapted resources to best optimise their medication-taking practices. A number of studies have looked into the risk factors associated with taking medications at home such as, under and over dosing medications, lack of medication

administration routine, hoarding, discontinued medication and therapeutic duplication, (Hsia der, Rubenstein, & Choy, 1997; Sorensen, Stokes, Purdie, Woodward, & Roberts, 2005). The positive aspect of medication use in the home, however, has not been well researched (Mager & Madigan, 2010; Read & Krska, 1998).

During the conversations with the Kōwhai household, I learnt about their strategies and routines around taking medications. This section discusses the development and adaption of resources that the Kōwhai household members have tailored to best optimise their medication-taking practices. These resources included a personal health diary, labelling their own medication and using a pill container to administer medication.

During the initial discussion with the household, Lana showed me Miriama's personal health diary. This diary was not something that was given to them or suggested by any health service or health worker; it was developed by Lana and her brother, Tāne. They used a plain A4 workbook to record their mum's daily life in relation to her health. This included the medication she was currently on, any appointments she may have had in the past and their outcomes, future appointments, daily logs from Whānau members, and anything else that they felt was relevant. In the extract below, Lana explains how the development of the health diary came about and how it serves to act as a valuable resource when they are consulting with medical staff. She also explains the specific structure of the book. The front of the book is for the daily journal and the back of the book holds all her medical notes and hospital discharge papers.

Lana: Because in terms of information, the medications will tell a health professional one thing but they won't necessarily give all the medical history, so the book goes with us everywhere. It goes to day care. It goes everywhere...

Facilitator: So is this book something that was told for you to keep?

Lana: No, we just keep the diary, we've got about 20 of these ... what happened was that she had a stroke and she went into hospital. And we would always visit and what not and sit with her. But she was in there for about six months in hospital going through rehab. And we didn't know who was coming and going and what the specialist was saying or whatever else so we started keeping the books and it's just gone on from there. So when she has a critical incident then it tends to be more medicalised.

And she'd have a little write in it from time to time. Kept all the clippings and what not. And these are her head exercises [pointing to a section in the book], finding names and nouns ... so that's basically the book in terms of a medical history and just the day to day what's happening today? Where did I go? Who saw what? ... at the back of the book is all the medical information ... all the discharge papers and what not, clinical notes ... and the thing is that she can be admitted into any hospital and it's not necessarily the same hospital all the time. So if they have problems with their records because they're not always centralised on the computer system. So it's easier for us to carry around the medical history.

Miriama's health condition is slowly deteriorating as she is regularly getting infections and the severity of her chronic illnesses are progressing, affecting her balance and immune system and symptoms persist for longer periods. Her medications are changing and new approaches are taken to address her current health condition. The journal is a vital resource in processing and keeping track of medication changes, GP and specialists recommendations. This practice shows that the management of medications are an integral part of the Kōwhai household's daily lives, as they work to document and understand medication use and make meaning of their experiences.

When the Kōwhai household was taking photos of their medication in the house, they specifically photographed the cat's medication on top of the fridge (as shown in Figure 5). When the household members discussed this photo, they talked about how Pango's (the cat) medication is specifically stored on top of the fridge by his cat food. When they place the medication on the kitchen bench, there has been confusion with the bottles, as Miriama's medication looks exactly the same as Pango's, and to add to the confusion, both the cat and Miriama take Warfarin. To eliminate any confusion with the cat's medication, Noi labelled each bottle and container that belonged to Pango with a cat illustration as shown specifically in Figure 6.



Figure 5: Pango's medication on top of the fridge.



Figure 6: Pango's medication with his own labels.

Taking the right medication is important to the Kōwhai household and, once in their possession, they alter the packaging to suit their practices and storage spaces, primarily to avoid any medication mix-ups. This practice shows that it was more important change the appearance of the medication rather than change their medication-taking practices. This illustrates the importance of routine and the extent to which efforts are made to integrate medications into daily lives.

Another resource that Lana and Miriama rely on is a small 'pill container', with this used to administer Miriama's daily medications. Lana discussed how the container is very important part of their daily routine. In the morning she places all Miriama's morning pills in the container, prepares her mums breakfast, and once Miriama has taken her pills, Lana give's Miriama her cup of tea. The pill container was introduced because when Lana would give Miriama her pills, she would place them in her hand and when she went to put them in her mouth, some of the pills would fall on the ground. The pill container provides a more functional way of swallowing all her pills. If the pill container is still in its storage place or the container still has pills in it, it also serves as a visual reminder that Miriama has not taken her pills. The pill container is a valuable resource in reminding and administering medication as it aids in the maintenance of taking medication on a daily basis. It aids in ensuring medications are taken, emphasising that medications are important to them.

The Kōwhai household used many medications and their state of health relied upon the fact that they needed to take their medication on a regular basis. As the household plainly stated, medications are a matter of life and death. Both Noi and Miriama have had long-term illnesses for many years, and due to their complicated medication regimes and related medical activity, the household developed resources and safety mechanisms to ensure they took their own medications and kept up-to-date with appointments. Using resources to maintain their medication regimes shows ingenuity and demonstrates the lengths they will take to incorporate medication into their everyday lives. Imrie (2004) discusses how the home is part of a person's mental and physical well-being as it provides privacy, security and functionality. The household structure allows allocation of functions to specific spaces, such as cooking in the kitchen. There are no specifically designed spaces, however, to accommodate disease and illness. Therefore, residents fashion their medication usage behaviours around the structure of the home and develop resources and strategies to best optimise their social practices with medication (Dupuis & Thorns, 1996; Dyck et al., 2005; Imrie, 2004).

Theme Eleven: Lay knowledge

Lay knowledge of health and illness is shaped by personal experiences, interactions with other people and broader cultural belief systems and shared culture or common understandings in society (Kelleher, Gabe, & Williams, 2006). Across each household, householders recited from their own knowledge base and understanding of medications. The householders with chronic illnesses had gained a vast amount of experience with medications as they went through many trial and error practices, to work out the best regime for them. In turn, they became lay experts, because ultimately they knew what medications and treatment methods worked for them and their lifestyles.

All the Kōwhai household members have a lot of experience with medications, whether it is related to their own intake or their whānau members. Noi has had a number of on-going illnesses since she was young and has used, misused and discontinued medication. Due to Noi's experience with her on-going illnesses, she is able to recite the medication she is currently on, why she is on certain medications and not others, and is able to explain how these medications affect her body. In the extract below, Noi is just beginning her initial interview and explains what her current medication regime involves and describes their uses.

Noi: Kia ora, where do I start? I'm 60 years old and I am a chronic asthmatic, I have Hepatitis C and I'm a cancer survivor. So all of those mean I have a lot of medication in my life. I've been on different types of bronchodilators and steroids and other things for asthma which I've been hospitalised for many times over many years ... the miracle drug for me at the moment is Symbicort which is a combination of reliever and preventer – the blue inhaler and the brown inhaler have been reconfigured into the red inhaler so I don't have to take shots from different devices. I only need the one, which I do twice a day usually if things are good. In flu season, I may have to take them up to five or six times and then I start using the blue one as well which is the dilator as well as the preventer. As you can see, I know quite a lot about the drugs that I'm on.

It would seem that Noi has a comprehensive knowledge of her illnesses and her medication, listens to her body, and adjusts dosages accordingly. Noi communicates that she knows a lot about her illnesses and associated medications, highlighting that her understanding and meanings of

medications is closely related to her experiences and lay knowledge. These pharmacological objects described by Noi are transformed in her dialogue as they represent social objects, they present her history of illness, memories of experiences with other medications, which help shape and form her current experiences with medications (Viswanathan & Lambert, 2005).

During household discussions, Lana spoke about the household's medications with great knowledge. She easily recalled what medication and devices each person was using and described in detail what medication related to each chronic illness and how the medication treated the symptoms. Lana explained that she gained her knowledge about medications from the numerous appointments and hospital visits she has had with her mum. Lana explained that she always asks questions when she is unsure about medications, procedures and her mother's care.

Lana: *"So I've gone through the process of knowing what Mum's medications are and what they're for and all the rest of it."* Medications are not seen as a personal responsibility in this household. They share responsibility and accountability for the use and knowledge of medications. Lana understands that her mother's welfare rests in her actions and care practices and understands that medications are a large part of making sure Miriama stays well.

Lana is especially familiar with her mum's medication and health illnesses. Lana not only learnt about her mother's medication from consultations with health professionals, but is also willing to take Miriama's medication herself to experience their adverse effects. Lana discussed how her mother was unable to go far from a toilet after she took a Furosemide pill and she wanted to be able to understand why. Lana: *"...so any way I popped one Furosemide pill and the earth shifted and I understood exactly what she meant that it was "I want to go right now." You've got to go to the toilet"*. This action allowed Lana to experience her mother's world. The understanding she gained from the experience enabled her to become more empathetic towards her mother's situation and her care needs. This action shows true commitment to understanding Miriama's experiences,

this enabled Lana to identify with her mother's requirements and recognise that she was legitimately in need.

As Lana oversees Miriama's medication regime and administers her pills, at times she has been in a situation where she had to decide what dosage of medication Miriama was to take because the Medical centres and Pharmacies were not open. As Lana explained, Miriama has weekly blood tests to monitor her Warfarin levels and depending on the results, her dosage levels can change. Due to Lana's experiences and numerous discussions with her GP and specialists about Miriama's dosage levels, she felt equipped enough to make a reasonable decision about Miriama's Warfarin dosage levels. This situation demonstrates the level of Lana's expert knowledge around Miriama's medication regime and exhibits the lengths she will go to insure her mother gets the right dosage amount of medication. Lana's experience with Miriama's 'medical world' has enabled her to make informed decisions about her health care needs, if deemed necessary. Lana's lay knowledge can be viewed as a type of insurance that Miriama is able to get the best care possible from her daughter (Read & Wuest, 2007).

Part of Lana's process in understanding the medication her household takes, is searching on the internet for information on medications components, adverse effects, effectiveness, and consumers experiences and opinions. Once Lana has analysed this information, she makes a decision on whether or not to consult with the GP further or begin the medication. On making an informed decision, Lana feels that she can forget about the details and particulars of the medication and move on.

Lana: You know, I just pop them [medication] ... I've read the information, I've gone to the website, I've looked at what all the side-effects are blah, blah, blah, blah, blah. Heard everyone else's stories of why they're on the medication, what it does to them, blah, blah, blah, blah, blah. And I feel fine about my medication and I can just forget that information. It's not irrelevant but it's too much detail, you know ... What I usually do is ... if Mum goes onto a new medication, I look at what that medication is. I find out what the side-effects are. I do a kind of search online because there's often forums with people who are also taking the same medication, they're having side-effects or stuff that they don't tell you about in terms of the side effect

official pages. And then weigh up what that information might mean. And then, you know, if all is fine, cool... So long as it hasn't got a huge controversy in terms of the drug that I'm on I'm happy about it ... But if it has then I usually go back to the ... doctor in question.

This process described above emphasises the commitment Lana has made to oversee her whānau well-being, through careful consideration of the facts around using certain medications. Responsibilities and commitments that Lana has demonstrated, are mirrored across cultures, socioeconomic status and geographic differences, where filial expectations of concerning care of aging parents persists (cited in, Donorfio & Sheehan, 2001). It is important to Lana that she has the resources to be able to access knowledge both physically and intellectually, as it enables her to become better informed about the medication she and her whānau use, enabling her to rationalise treatment decisions.

The Kōwhai household is rich with knowledge around medications as two household members have a number of chronic illnesses and are heavy users of medication. Noi demonstrated that, through her vast and long-term experience with medications, she has gained a lot of lay knowledge around her illnesses and consequently become an expert on her own health conditions. As Miriama's carer, Lana acts as an advocate for her mother by becoming knowledgeable about her mother's condition, attending medical appointments, seeking advice from medical professionals, personal experience and researching online. The knowledge acquired helps reduce the turmoil associated with the uncertainty about Miriama's ever-changing health status (Boland & Sims, 1996; Read & Wuest, 2007), as Lana became better informed about the associated treatment methods, medications and adverse effects.

These avenues of knowledge help inform Lana on the care practices she should take and legitimate her position as a carer and Miriama's illnesses (Nichter & Thompson, 2006). Being able to question medical advice and research online enables Noi and Lana to gain an understanding into why one experiences adverse effects, why certain pills are prescribed or why

specific tests need to be performed. Understanding enables individuals to have a sense of control about their health and become involved in the decisions made by health professionals.

Read and Wuest's (2007) study discussed how daughters that accumulate knowledge about their parent's chronic illness are striving for control, as there is a sense of future loss and disruption to the family unit. This concern triggers protective watchfulness and caution around the treatment options, including use of medications, in the context of approaching unwellness and loss (Read & Wuest, 2007). This may be the case for Lana, however, interpretation of why one cares for another is a complex multidimensional construct, where multiple perspectives are in play including cultural expectations and values such as reciprocity, gift of exchange and whānau responsibilities. Therefore, gaining insight in the Kōwhai households understanding of medications requires consideration of the practiced relationships within the household.

Household summary

Briefly, the Kōwhai household had their own unique history with medications. As a household, they experienced adversity with medications, in some instances provided solace in their life, while other medications reduced their independence. These experiences with medications created a knowledge base, enabling the household to learn from past experiences. The household became experts on their own bodies and developed knowledge and intuition with those they cared for. Experiencing adversity encouraged them to seek answers for themselves. They became more informed on the health care decisions suggested by medical professionals. This in turn enabled the household to create routines and strategies that best suited their home space and lifestyle, and allowed them to accept that medications were a part of their lives and existed within the relationships they have with each other. Medications presented more than substances, they symbolised notions of hope, history, aroha and care and which in turn gave the medications 'social

lives' and meaning (Bauman, 1996; Olsen, 2003; Sointu, 2006; van der Geest, Whyte, & Hardon, 1996).

Summary of findings

This research aimed to explore householder knowledge of medications, how medications work, and what it means to take medication.

Furthermore, the research aimed to document social practices involving medications within households, such as how, when and where they are used, and how they are accessed and distributed.

Medications in this study were used as a focal point to enter into the everyday lives of those families who live with, and manage, chronic illness. Entering into four separate domestic domains and listening to differing circumstances around the social practices with medications, lead to a multifaceted analysis, which mirrored the complexity of everyday life. During the analysis process eleven underlying themes emerged, each household presenting a slightly different perspective and context to the themes. These themes were also more or less prominent according to the households' experiences with medications.

Focusing on these eleven themes presented clear indications of what medications mean to Māori households. Firstly, across all the households it was evident that medications are managed within their homes. The findings are consistent with literature which acknowledges that the management and adaption to chronic illness at home can create stress, as it requires adaption by the individual and family members (Newby, 1996). This study found that homes do not have specifically designed spaces to accommodate disease and illness. Residents fashion their medication usage behaviours around the structure of the home and develop resources and strategies to best optimise their social practices with medication. Households created routines and strategies that best suited their home space and lifestyle, and allowed them to accept that medications were a part of their lives and existed within the relationships they have with each other. Homes were used as care sites in which

medications become objects of care through the enactment of relationships with other householders.

The importance of relationships was a key theme presented across the household's, relationships with others was an integral part of managing chronic illnesses, including the management and use of medications. Reliance on others gave rise to care and support relationships within the households as a mother cared for her daughter, a daughter cared for her elderly mother and a son cared for his wife and his elderly parents. Support and care also presented as a husband and wife allowed each other to express their rangatiratanga. Although the perspectives on medication management and use differed, care and support was still present as they gave each other the space to practice their understandings of medication management, while offering manaakitanga.

Cultural values played a vital role in the social structure within the homes as household members communally cared for each other. The dependent were looked after by loved ones and filial relationships were bound together by responsibility, duty and care. Medications became subsumed within these relationships as a part of the everyday practice of caring for another, becoming cultural objects. Within these Māori households, medications were viewed as what I refer to as 'personal' prescriptions and 'whānau' prescriptions. In the first instance, medications were prescribed to the individual person for their health benefit and maintenance. They were also prescribed within a whānau environment, however, where loved ones supported and cared for each other by developing and maintaining medication regimes and resources, administering and applying medications and gaining knowledge on medications. Factors such as accessibility of medications, cost, medication effectiveness and adverse effects were perceived, understood and managed within the whānau. Household members would alter their daily routines to allow medication side-effects to wear off or alternatively take medications at differing times.

Medications were more than just substances, they symbolised notions of hope, history, aroha and care and which in turn gave the medications

'social lives'. The findings are consistent with the premise that medications are material objects with therapeutic uses that enter into, and take on meaning within people's lives. They are culturally embedded phenomena that carry meanings and shape social relationships and practices.

In the concluding chapter, I will discuss the importance of relationships and care in Māori households and how they contribute to the management of chronic illness. Next, I will explore the contributions this research can make to the current body of medication literature. Finally, the future research directions will be covered.

CHAPTER FOUR: DISCUSSION

Chronic illness is a significant health issue for Māori. Through advancements in medical technology, people are living longer and medications are used to prolong life and manage chronic illness (World Health Organisation, 2005). The shift from acute to chronic illness is no longer isolated to the hospital setting as chronic illnesses are increasingly being managed in domestic settings (Edward et al., 2001).

The primary objective of this research was to advance knowledge about the meanings of medications in Māori households and the social practices that surround medication use. Even though Māori were specifically targeted in this research, they did not present as a homogenous group. The meanings of medications are complex. Medications are understood as functional objects, to maintain health and prevent illness. Medications have become cultural objects as they are used in a way that reflects the cultural values and bonds within the households. Within household relationships, medications are invested within meaning to show aroha, support and care. Within a Māori whānau context, the values of maanakitanga, rangatiratanga, and whanaungatanga were recognised as having an integral role in understanding the social practices with medications in each household.

The eleven key findings from this research illustrate the complexities involved in the consumption of medications and the dissolving of these pharmacological and social objects into cultured domestic contexts, bodies and relationships. This chapter reviews the ways in which Māori households manage their medications in relation to their understandings of these objects. I then bind key elements together, discussing the familial relationships within these household as central elements for the context of care and identity, while considering the value of whānau and how it informs contemporary care giving practices in the home. This leads to an exploration of how the severity of one's chronic illness can impact on the way in which medications are understood and the different meanings for

their users. Consideration is then given to how this research provides knowledge of Māori use of medications in the home that can inform medical professionals. Finally, future directions for research are offered.

Caring, managing chronic illness and culturally patterned relationships

The centrality of familial relationships of care to the management of chronic illness through medication use, supports a relational understanding of health. This perspective posits that health is fundamentally relational and as dependent on social arrangements as biological processes (Hodgetts, Sonn, Curtis, Nikora, & Drew, 2010). Such a stance is supported by decades of epidemiological research that shows that the more functional and supportive the relations between groups in a society and the more social cohesions there is the healthier the entire population (Wilkinson & Pickett, 2009). This thesis has contributed to work in this area by demonstrating the importance of relationships to the management of chronic illness in Māori households.

In this context, medications represent more than inanimate objects; they are diverse and are understood and used by people in everyday life in ways that transcend their categorisation as prescription drugs (Doran et al., 2005). Medications not only relieve symptoms and allow the maintenance of a certain level of health; they enable people to gain a sense of control over the uncertainty of illness and to experience support. Medications become central to the ways in which people care for one another, how they show their aroha and help fulfil responsibilities (Nichter & Thompson, 2006). During the analysis process, it became evident that there was an ever-present underlying theme related to the importance of relationships and care in the management of medications.

In the Harakeke, Pūriri and Kōwhai households, it was clear that if the relationships were not present, the chronically ill would not survive. Additionally, in the Pohutakawa household there was a high probability that the chronically ill may develop dependency, where relationships with

others would be paramount to the survival of the chronically ill. During the research, household members described how they cared for each other. Certain household members took on the responsibility of obtaining information on medication, the administration of medication, storing the medication, and attending medical appointments with their whānau. This allowed the carers to ask questions about medications and help suggest changes in the medication regime. These actions and events created situations where responsibility, duty and care practices were performed and reciprocated as whānau members had been cared for in the past.

Throughout the household discussions, caring relationships were based on reciprocity, manaakitanga, aroha and responsibility. However, when exploring literature on care giving in the home, it was described as a being burdened with extra responsibilities, having to worry about another; having to place own aspirations and needs on hold (Boland & Sims, 1996). Care was described as having many negative aspects from feeling weighed down by responsibilities, not having enough support and resources, and the emotional stress it gives rise to (Boland & Sims, 1996; Donorfio & Sheehan, 2001; Read & Wuest, 2007; Voysey Paun, 1975). However, in the context of this project, the notion of 'care' was reciprocal in nature, as people have to want to be cared for and responsibility for others seen as collective, caring while possibly felt as a burden was constructed by these participants as a privilege leading to the fulfilment of filial responsibilities. While this may contrast with the literature about 'caregiver burden', further investigation of this pattern is required.

Tying key elements together: Domestic emplacement, identity, cultural values and Māori chronic illness

Presently no one has studied medications within Māori households, how Māori people understand medications and how this impacts on social practices with medications. Studies such as Baxter (2002), Davis and colleagues (2006), Ellison-Loschmann and Pearce (2006), Harwood and colleagues (2005), Ministry of Health and Wellington School of Medicine

(2005), and Willams and colleagues (2003) have focused on specific chronic illnesses, which explore the barriers to healthcare for Māori, health seeking behaviours and the prevalence of specific ailments. The present study provides insight into the everyday lives of those with chronic illnesses where medications take on important meanings for users at home, enabling people to respond to illness and engage in the management of health.

This research has also extended present understandings of the chronic illness experience. This study demonstrates that experiences with chronic illness transcends personal reactions (Pinder, 1990), self-perceptions (Charmaz, 2002) and physical reactions (Shoemaker & Ramalho de Oliveira, 2008). Experiences are also influenced by social interactions, where relationships become a focal point in the care and maintenance of illness. Literature on social impacts of the chronic experience such as Anderson and Bury (1988), Chamberlain and colleagues (2007), and Cohen and colleagues (Cohen et al., 2001), recalled social experiences as having an impact on the way one may react to issues of identity change and responsibilities, where they may influence choices and actions. However, little acknowledgement is made into how social experiences influence the health and management of the condition, furthermore, the importance of relationships within the home.

In the Harakeke, Pūriri and Kōwhai households, participants discussed how medications fitted into their lives and represented more than just a lotion or a pill, enabling them to feel like they were actively helping another. Medications not only have medicinal purposes but legitimated illness that gave rise to more explicit care relationships as those on medications were considered to be in genuine need (Whyte et al., 2002) and worthy of assistance. As material objects situated in specific domestic locations, medications are intertwined with people's practical experiences of being in the world, routines, habits and memories (Olsen, 2003). Through daily practices involving the use of medication, people come to know and understand themselves (Heidegger, 1982). Olsen (2003) proposes that "...we are always already in the world; the world is part of

our being, not something external, 'out there' to eventually be embodied. We are not detached observers of objects, but concerned users of things..." (p. 96). People are interwoven into the world through the use of a collage of material objects that they often simply take-for-granted until these do not serve their purpose. Medication emplacement and use constitutes statements of self and relationships with others, including family and health professionals. Householders develop 'a sense of place' where memories are associated with particular locations and objects (Dyck et al., 2005). Such places and associated tactics furnish people with a sense of connection; history and shared activity (Twigger-Ross & Uzzell, 1996) with each other; places and homes serving to position the chronic illness and what it means centrally within these relationships.

Householder routines and daily practices with medications become customary within the home. Such practices include, storing medication in a certain place in the bedroom, bathroom or kitchen to remind the person to take their medication. Throughout the households, people and those who care for them strategically placed their medication in areas of the home where they would be seen and noticed, thus prompting them to take their medication. Practices such as simply reminding Dad or Mum to take their medication by placing medications in a pill container in front of them, or on the dining room table, constitute material statements regarding familial relations, routine, concern and care. As part of caring, reminding, remembering and asking for compliance are social activities often expressed through culturally defined behaviours that demonstrate affection, affiliation and humour in exchanges surrounding the use of medications. They become expressions and engagements of manaakitanga and whanaungatanga. Caring through placement and memory prompting reflects how simple acts have a broader significance in social relationship surrounding medication use and how these actions reflect and support Māori values. Cultural obligations are met through enactments of giving others their medication, strengthening bonds and commitments, in turn preserving the integrity and strength of the family.

For Māori, the cultural values of manaakitanga, rangatiratanga and whanaungatanga define kinship obligations. As a lens through which to view relationships, manaakitanga provides understanding of practices of care and support householders had for one another, as loved ones reminded each other to take medication, attended medical appointments with them, and provided support to make lifestyle changes and maintain routines. Rangatiratanga highlighted how aroha, status and respect can play an integral part in the way medications were used, as care for the elderly was conducted in such a way that endeavoured to uphold their status and mana, which was simply illustrated in the way a son addressed his father during the interview. When taken together, these values bring about an obligation on the part of children to reciprocate earlier care provided by their parents and grandparents, in turn enabling the aged to discharge their cultural responsibilities as elders (Ritchie, 1992). Furthermore, elders have to want to receive care, for example, John did not seek care from others as he felt he was physically well enough to look after his own health.

The importance of considering the severity of illness

Meanings of medications are linked to the relational practices and cultural patterning in the home describes pattern that prescribes Māori ways of domestic life. The severity of one's illness can also play a vital role in what medications mean to the household. It was evident that the severity of one's illness influenced the associated meanings individuals and their whānau gave to medications. Such views affected all facets of use and understanding, as medications were seen as either a necessity or a choice to take. Medications were perceived on a continuum from being life saving, through to having no impact on the illness and its symptoms, thus affecting the impact medications had on their daily life. The severity of illness also impacted on whether routines and resources were developed and maintained.

Individuals that had severe chronic illness, or more than one illness, were more likely to be dependent on their medications to keep them alive. This dependence, affected their approach to medications, because the use of these substances meant the difference between life and death. If medications were not taken routinely, their health would deteriorate rapidly. The importance of taking medications on a regular basis was an important priority for the individuals who had severe chronic illnesses. Medication and health care needs were prioritised in terms of creating care spaces within the home, and developing and maintaining routines. Conversely, less dependent medication users, understood medications as less of a prominent feature in their everyday lives. When medications were not taken, or applied as directed, and/or no immediate or short-term effects were experienced, users perceived medications as being both ineffective and prescribed use as more of an ideal, rather than a strict requirement. This practice of medication use lead to a cyclical process where medications were not used as prescribed, therefore were not able to potentially function as designed, which fed into the perception that medications were not effective. In the context of everyday life for the less dependent users, medications took a backseat to priorities in their life; they were used and understood as additional annoyances that were begrudgingly taken.

Those with chronic illnesses can experience different stages of symptoms in their health depending on the risk, severity and impacts of their condition at any one time (Edward et al., 2001). Medication use can either change depending on the proximity of risk to health and past experiences also play a factor in how medications are used and understood. For example, prior to Tui experiencing two heart attacks medications were not perceived as a necessity, however, the impact of almost dying, changed Tui's perception, where medications became a priority in his life with the help and support of his whānau. The broader implications of this finding acknowledge that whānau play a vital role in the prevention, implementation and maintenance of health care including the management of medications. Furthermore, this highlights the importance

of relationships and that when professionals prescribe medications or advise individuals they need to be aware that these enter into social negotiations within households.

General implications

Medications have multiple existences. Once in the hands of sick people they represent relief from suffering, maintenance of health, but they also constitute identities, moralities, routines, relationships, care, healing and home-making (Doran, Robertson, & Henry, 2005; Pound et al., 2005; Shoemaker & de Oliveira, 2008). In this study, I set out to explore the meanings of medications in Māori households with chronic illnesses. I found members of households supporting each other to take medications, care spaces and routines were created to support the chronically ill and lives were structured around customary relationships, and obligations of respect and care. Medications become cultural objects that were used within filial relationships used to nurture and care for others. Relationships within the households were paramount to the social practices with medications in the home and the success of the management of medications. This finding fits within the premise that health is relational as well as physical, psychological and environmental (World Health Organisation, 1986). According to Mason Durie (2004), health is relational in that it requires a balanced and supported life that embraces physical wellbeing, social support, whānau, cultural participation and spirituality.

What is clear from the findings is that to understand what medications mean to Māori households we need to engage more directly with the specific practices, beliefs, environments and relationships, which embody the social lives of medications. Understanding, what role whānau play in the management of chronic illness can inform how the households can be supported and resourced. This research has highlighted that the patient and their whānau play a central role in their health care. Supporting self-management in the home is an important aspect to chronic care, as it will enable people to become partners in the process of health management

and allow the whānau to be included in the health care process of their loved ones.

Māori with chronic illnesses and their whānau have a vital role in managing the illness. When involved in care planning, whānau may support behaviour and lifestyle changes. For people and whānau to manage more effectively and safely at home, they need to develop knowledge and understanding of their condition. Just as the Pūriri and Kōwhai households have obtained and integrated knowledge on the medications used in the household, whānau need support to understand what they can do to keep themselves well, manage symptoms, slow their condition's progression, and when to seek help. This approach involves re-orientating the health system to provide better and earlier support for people to live well with chronic illnesses and long-term conditions as medications are prescribed into the lives of whānau, not just on the life of a sick person.

This thesis exemplifies that cultural values requires much greater consideration in the formulation of policies and social services that address Māori approaches to medications. Such work is crucial at a time when the health disparities are only increasing among Māori in New Zealand and with increasing pressure on social welfare and health care budgets. Situating culture in larger society and attention on interpreting social issues through the cultural lenses of those concerned will expand responsiveness of policymaking and elder care.

Future research directions

This is the first ethnographically oriented study of medication use in Māori households with chronic illnesses. Offered is a perspective that extends beyond individual experiences with specific illnesses to the ways in which these medical technologies are integrated into relationships and take on meaning. This made it difficult to compare the present study against an established body of knowledge. Research on medication use and meaning is dominated by quantitative research methods that have a tendency to

collect a much narrower with limited engagement with the realities of everyday life.

Findings from this study indicate that the management of chronic illnesses and medications are significantly influenced by the relationships within the home; householders relied on each other for care, access to medications, management of routines and assistance. Therefore, the identification of potential support avenues, to enhance care relationships within households with chronic illnesses, need to be explored. Support initiatives are essential part of maximising the emotional, psychological, and technical resources needed for complex care giving and to ensure that family members do not deplete their own physical and emotional reserves (Ministry of Health, 2010).

Briefly, evidence-based interventions are urgently needed where it will supplement the care receiving experience for patients and their whānau, considering the importance of Māori cultural context. It is hoped that this study will serve as a platform for understanding that healthcare in Māori households is relational and the need to support those who care for others is vital to managing chronic illness.

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Appendix A: Medications in Everyday Life Information Sheet



THE UNIVERSITY OF
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Te Whare Wānanga o Waikato

Medications in everyday life

Information Sheet

What is this research about?

Medications are widely available and commonly used by many people in New Zealand today. However, we know very little about how medications are understood by people, and how they are used in people's homes. This research aims to investigate popular understandings of medications and their uses. It is concerned with medications of all sorts – prescription medicines, over-the-counter medicines, alternative medicines and dietary supplements. It is important to note that we are not interested in any form of illegal drugs. The research is being undertaken by a team from Massey, Waikato, Otago and Victoria universities and is currently funded by grants from the Health Research Council and the Royal Society of New Zealand.

What is involved?

We are seeking to work with households of least three people, including an adult (16 or older) who has been diagnosed with a chronic illness and has been taking medication for at least 6 months. We have a number of tasks, outlined below, that we would like to complete in each household, although it may not be possible to do every one of these in any particular household. Which of these we complete in each household can be decided by the household members involved.

The specific components of the research are:

Initial household discussion

First, we will hold a household discussion with all members of your household who are interested to participate. This will take place in your home, and involve a general discussion about medications, their meanings and what you do with

them. We will also ask you about all the medications in your home, and to draw a rough plan of your house and locate on it the places where you keep medications. We would also like to photograph these settings and link them to the plan, but we will only do this with your permission. We would also like to see the range of medications, and related things like pill organisers and inhalers, that you have in the house, but only those things you are willing to show us. The discussion will be digitally recorded and transcribed so that the research team can complete their analyses. This meeting should last around two to two-and-a-half hours altogether.

Then we have three different projects that we would like different people within the household to complete. Anyone who is 16 years of age or more could do these, and it is not essential that we do all of them – it depends on how many people are present and who is interested to do each.

a) Carrying out a photo project

One person from the household will be asked to take photos of anything about medications – photos that show us “the world of medications”. We will provide detailed information on what is involved in this process. Photographs can be taken on your own digital camera or we can give you a disposable camera. These photographs will be printed and discussed in a recorded interview with the person who took them. The person will have two weeks to take the photographs, and the interview to discuss the photos will take about one hour.

b) Keeping a medication use diary

One other person in the household, preferably the person with the chronic illness, will be asked to keep a medication diary. This involves keeping a daily record of any medications taken each day for a week, and writing brief notes about that at the end of each day. We will provide detailed information on what is involved to this person. The person will then discuss the diary content with us in an interview after the week is over. This should take no more than three hours altogether, including the interview of about one hour, which will be recorded for analysis.

c) Keeping a general medication diary

Another person in the household will be asked to keep a diary for one week, noting any time that medications of any sort come to attention in any way (while watching television, reading magazines, shopping, and so on – wherever medications come to attention). At the end of each day, this person will select one issue and write a little about it. Again, we will provide detailed information on

what is involved to this person. After the week is over, we will have a meeting with that person to discuss the diary entries. This should take no more than 3 hours altogether, including the one hour interview which will be recorded for analysis.

Finally, after these tasks are completed, we will have a closing household discussion with everyone involved to review the project and to gather reactions and comments from household members. This discussion will take less than 2 hours, and will also be recorded for analysis. Your household will be given a \$100 voucher after the closing discussion as compensation for all the time this will involve.

How can you participate?

You are invited to take part in this study if your household includes at least three people, one of whom who has been diagnosed with a chronic illness, has been taking medication for at least 6 months and is 16 or over. If this is the case, please discuss the project with members of your household and then contact Teah Carlson from University of Waikato to discuss your participation. Her contact information is given below. She will answer any questions you have and make a time to come and meet with the members of your household who are interested to participate.

What are your rights if you decide to participate?

If your household is willing to take part in this research, you should know that all the information you provide during the study will be kept completely confidential. All the data will be stored in a secure place, and no one other than the researchers will have access to it without your consent. Your names will not be used to identify the materials, or used in any reports that come out of the research. Any personal or identifying features that are mentioned will be altered to make sure that everyone remains anonymous. The materials collected in the study will be used in the analysis for the research, and brief extracts from the interviews or diaries may be used in publications and presentations arising from the research. However, we will take care to ensure that these will not identify you in any way. We may also use the house plan and photographs in publications and presentations from the research, but these would have all identifying features masked.

You should also know that you have the following rights:

- *Members of your household do not have to take part in this study at all, or in any specific component of it; anyone is free to decline.*
- *Members of your household can ask questions about the research before agreeing to take part, and anyone who agrees to take part can ask questions about the research in general, or any specific component of it, at any time during the study.*
- *Anyone taking part in the research can decline to talk about any issues, during any of our discussions.*
- *Anyone taking part in the research can ask for the recorder to be turned off at any time during discussions.*
- *Your household can withdraw completely from the study up to two weeks after our closing discussion. If you do, all recordings, transcripts, your house plan, and any photographs taken will be destroyed.*
- *You can request a summary of the findings to be sent to your household when the study is concluded.*

How can you contact us?

Supervisor:
Dr. Linda Waimarie Nikora
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If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, email r.isler@waikato.ac.nz)

Appendix B: Medications in Everyday Life Consent Form



Research reference:

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THE UNIVERSITY OF
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Te Whare Wānanga o Waikato

Medications in everyday life

Consent Form

We have read the Information Sheet and have had the details of the study explained to me. Our questions have been answered to our satisfaction, and we understand that we may ask further questions at any time.

We agree to participate in this study under the conditions set out in the Information Sheet.

We also consent for data from this project, with all identifying features removed, to be archived for further research projects and teaching purposes

Yes No

Date: _____

Signature:

Full name (printed):

Signature:

Full name (printed):

Signature:

Full name (printed):

Signature:

Full name (printed):

Signature:

Full name (printed):

Signature:

Full name (printed):

Would you like to receive a summary of the results? Yes No

Name:

Email address:

Or

Postal Address:

If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, email r.isler@waikato.ac.nz)

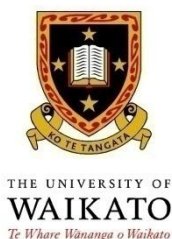
Appendix C: Interview Schedule for the household discussion

Topics for household discussions

The following list of topics to be covered by the researcher during the initial household discussion:

- The meanings of medications (primary focus)
- Personal medication use, including the use of alternative medications and supplements, and storage (who in the household takes medications, what medications are taken, where and how are they taken, what are they used for, where are they stored in the home)
- The flow of medications through the household and beyond (how the medications arrived, if and how medications move beyond the house, how are medications disposed of)
- What material objects in the home are related to medication use (e.g., first aid kits, glucose meters, asthma inhalers, storage containers)
- Uses beyond the prescribed
- Medications beyond prescription (supplements, pharmacy only, OTC, alternative – include inhalers, topical creams)
- Issues of prevention/promotion/maintenance/cure (relation between)
- Morality – good/bad – Why? How?
- Risk – safety, compliance, responsibility
- Personal approach to medications (resisting/passive or active acceptance, etc)
- Relationships involving medications (sharing, caring, taking, nagging)

Appendix D: Medication Use Diary Information Sheet



Medications in everyday life

Medication Use Diary Information Sheet

What is this part of the research about?

You have already agreed to be the person in your household who will take part in the medication use diary project for the research. In this part of the research we would like you to keep a diary recording all the medications you take or give to others in the household each day for a week. This includes medications of any type – prescription medicines, over-the-counter medicines, alternative medicines, dietary supplements, health care remedies. Also, at the end of each day, we would like you to think about one episode of medication use from that day and write brief notes or comments on that episode. We will give you a diary to record the daily medications use and you can use this to write your brief daily comment if you wish. Alternatively you could keep your comments on an audio recording or typed onto your computer, as you chose. This diary will then be the focus for a personal interview at the end of the week, where the meanings of your diary entries will be discussed. The interview will be conducted by Teah Carlson, will take about one hour, and will be recorded and transcribed for analysis.

What are your rights if you decide to participate?

The information you provide in the diary and the interview will be kept completely confidential, and any personal or identifying features will be altered to ensure anonymity. All the data will be stored in a secure place, and no one other than the researchers will have access to it without your consent. Your name will not be used to identify the materials or in any reports that come out of the research. The materials collected in the study will be used in the analysis for

the research, and brief extracts from the diary and interview may be used in publications and presentations arising from the research.

You should also know that you have the following rights:

- *You are under no obligation to take part in this project.*
- *You can ask questions about the research before agreeing to take part, and about the project at any time during the study.*
- *You can decline to talk about any issues during our discussion.*
- *You can ask for the recorder to be turned off at any time during the discussion.*
- *You may withdraw from the project up to two weeks after our discussion. If you do, the recording of our discussion and your diary will be destroyed.*

How can you contact us?

Supervisor:
Dr. Linda Waimarie Nikora
Māori & Psychology Research
Unit,
Department of Psychology
Faculty of Arts and Social
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If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, email r.isler@waikato.ac.nz)

Appendix E: General Medications Diary Information Sheet



Medications in everyday life

General Medications Diary Information Sheet

What is this part of the research about?

You have already agreed to be the person in your household who will take part in keeping a general medications diary for the research. In this part of the research we would like you to keep a diary recording any time that medications of any sort come to attention in any way (while watching television, reading magazines, shopping, and so on – wherever medications come to attention). This can include medications of all types – prescription medicines, over-the-counter medicines, alternative medicines, dietary supplements, health care remedies. Also, at the end of each day, we would like you to think about one episode when medications came to your attention that day and write brief notes or comments on that episode. We will give you a diary to record these daily medications episodes and you can use this to write your brief daily comment if you wish. Alternatively you could keep your comments on an audio recording or typed onto your computer, as you chose. This diary will then be the focus for a personal interview at the end of the week, where the meanings of your diary entries will be discussed. The interview will be conducted by Teah Carlson, will take about one hour, and will be recorded and transcribed for analysis.

What are your rights if you decide to participate?

The information you provide in the diary and the interview will be kept completely confidential, and any personal or identifying features will be altered to ensure anonymity. All the data will be stored in a secure place, and no one other than the researchers will have access to it without your consent. Your name will not be used to identify the materials or in any reports that come out of the research. The materials collected in the study will be used in the analysis for

the research, and brief extracts from the diary and interview may be used in publications and presentations arising from the research.

You should also know that you have the following rights:

- *You are under no obligation to take part in this project.*
- *You can ask questions about the research before agreeing to take part, and about the project at any time during the study.*
- *You can decline to talk about any issues during our discussion.*
- *You can ask for the recorder to be turned off at any time during the discussion.*
- *You may withdraw from the project up to two weeks after our discussion. If you do, the recording of our discussion and your diary will be destroyed.*

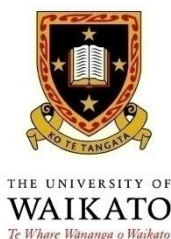
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If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, email r.isler@waikato.ac.nz)

Appendix F: Photo Elicitation Information Sheet



Medications in everyday life

Photo Information Sheet

What is this part of the research about?

You have already agreed to be the person in your household who will take part in the photo project for the research. In this part of the research we would like you to take photos of anything about medications – photos that show us how you see “the world of medications”. These photographs may be about any aspect of medications that you want to show – we do not have any specific expectations about the nature or type of photographs you might take, only that they will involve medications in some way.

The photographs can be taken on your own digital camera or we can give you a disposable camera. You should take the photographs over the next two weeks. Please note that you may take photos of people in public places, but you must obtain their consent to take photographs of them when they are not in public places. Once you have taken around 15-25 photographs, please get in touch with me, Teah Carlson, and let me know you have completed the project. I will then make a time that is convenient to discuss your photos with me. This discussion will cover the meanings of the photos and what you consider they show about medications. It will take us about one hour and will be recorded and transcribed for analysis.

What are your rights if you decide to participate?

If the photographs you take involve identifiable people we will mask their features to ensure that they cannot be identified. The information you provide during the interview will be kept completely confidential, and any personal or identifying features will be altered to ensure anonymity. All the data will be stored in a secure place, and no one other than the researchers will have access to it without your consent. Your name will not be used to identify the

materials or in any reports that come out of the research. The materials collected in the study will be used in the analysis for the research, and brief extracts from the interview and some photographs (with identifying features masked) may be used in publications and presentations arising from the research.

You should also know that you have the following rights:

- *You are under no obligation to take part in this project.*
- *You can ask questions about the research before agreeing to take part, and about the project at any time during the study.*
- *You can decline to talk about any issues during our discussion.*
- *You can ask for the recorder to be turned off at any time during the discussion.*
- *You may withdraw from the project up to two weeks after our discussion. If you do, the recording of our discussion and your photographs will be destroyed.*

How can you contact us?

Supervisor:
Dr. Linda Waimarie Nikora
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teah.carlson@gmail.com

If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, email r.isler@waikato.ac.nz)

Appendix G: Medication Use Diary Consent Form



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Research reference:

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Medications in everyday life

Medication Use Diary

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to participate in this study under the conditions set out in the Information Sheet

Signature: _____ Date: _____

Full Name – printed

If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, email r.isler@waikato.ac.nz)

Appendix H: General Medications Diary Consent Form



Research reference:

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THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Medications in everyday life

General Medications Diary

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to participate in this study under the conditions set out in the Information Sheet

Signature: _____ Date: _____

Full Name – printed

If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, email r.isler@waikato.ac.nz)

Appendix I: Photo Elicitation Consent Form



Research reference:

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THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Medications in everyday life

Photographs

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to participate in this study under the conditions set out in the Information Sheet

Signature: _____ Date: _____

Full Name – printed

If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, email r.isler@waikato.ac.nz)

Appendix J: Photograph table

Table 1.

Photograph table

Photograph Reference	People	Place	Object
Household 1, Photo 1	-	Kitchen bench	Jug, plates, plant, medication bottles
Household 1, Photo 2	-	Kitchen pantry	Cans of food, plastic containers, panadol packet
Household 1, Photo 3	Megan	Living room bookshelf	Books, soft toys, medicated creams

