

**The Experience of
Primary Healthcare Patients
Who Take Warfarin
in New Zealand**

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ABSTRACT

Title: The experience of Primary Healthcare patients who take Warfarin in New Zealand.

Background: Warfarin therapy is an integral component of Primary Healthcare and is considered underutilised. Primary Healthcare nurses are predominantly involved with long-term monitoring and collaborative management of Warfarin therapy. This research emanated from the paucity of qualitative research on patients' own experience. The aims of this study were to explore Primary Healthcare patients' experience of initiation, monitoring and education of Warfarin. To explore patients' beliefs, issues, concerns and behaviours regarding Warfarin, as well as exploring patients' understanding of their relationships with Primary healthcare professionals.

Methodology: The sample included four males and six females: eight who identified as New Zealand European and two New Zealand Māori. Ages ranged from forty - two to eighty-six years. Warfarin had been prescribed between six months to twenty-eight years. A qualitative inductive methodology adapted from Thomas' (2003) framework was utilised to enable the participant's experience and a deeper understanding to be illuminated. An inductive method enabled a straightforward, comprehensible and orderly procedure for data analysis, allowing an emergence, identification and interpretation of themes without confinement. The researcher used reflection to reduce bias and recognise the influence of prior experience to permit a true reflection of the participant's perspective.

Results: Inductive data analysis revealed six key interrelated themes. These themes were impact, self, knowledge acquisition, information/misinformation, education and health professionals.

Conclusion: Warfarin therapy encroaches significantly into patients' lives. Repercussions of Warfarin therapy are evident in many facets of life, not just health. Individual variance requires integration into practice of personality, differing learning styles and diversity of cultural health perspectives. Primary care was valued

as it provided trust, continuity of care, empowerment and ease of access. Nurses make positive contributions to patients on Warfarin; however, there is a possibility of role development. This is the first New Zealand qualitative study to highlight patients' experience of Warfarin therapy in Primary Care.

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LIST OF ABBREVIATIONS

A-fib	Atrial fibrillation
AVR	Aortic Valve Replacement
CCN	Canterbury Clinical Network
CDHB	Canterbury District Health Board
CHD	Coronary Heart Disease
CVA	Cerebro-vascular Accident
CVD	Cardiovascular Disease
INR	International Normalised Ratio
LTC	Long-Term Condition Management
MoH	Ministry of Health
NCNZ	Nursing Council of New Zealand
NZ	New Zealand
NZHCS	New Zealand Health Care Strategy
PHC	Primary Healthcare
PHO	Primary Health Organisation
PHCS	Primary Health Care Strategy
SIA	Services to Improve Access
USA	United States of America
WHO	World Health Organisation

GLOSSARY OF TERMS

Adherence – Process whereby patient's follows prescription and recommendation for a regimen of care. There is a need for agreement and the patient is free to decide whether or not to adhere (Harris, Nagy, & Vardaxis, 2006; Nunes, et al., 2009).

Anticoagulant – a substance that prevents or delays coagulation of the blood (Harris, et al., 2006).

Antiphospholipid syndrome – an autoimmune disorder characterised by thromboembolism and pregnancy loss in combination with antiphospholipid antibodies (Harris, et al., 2006).

Atrial fibrillation – a cardiac arrhythmia characterised by disordered electrical activity in the atria, accompanied by a usually rapid, irregular ventricular response. The atria quivers instead of pumping in an organised fashion. Stasis of left atria flow increases the risk of stroke (Harris, et al., 2006).

Beneficence – ethical principle to exhorting people to act in others best interests (Harris, et al., 2006).

Bio-availability – the degree of activity or amount of an administered drug that becomes available for activity in the target tissue (Harris, et al., 2006).

Bioequivalence – pertaining to two formulations of the same drug that attain similar concentrations in blood and tissues at similar times with no clinically important differences between their therapeutic or adverse effects (Harris, et al., 2006).

Care Plus – a primary healthcare initiative targeting patients with chronic medical condition, acute medical or mental health and aims at chronic condition management, reducing inequality, promoting teamwork in primary healthcare while reducing the cost of healthcare (Ministry of Health, 2012).

Compliance – The extent to which the patient’s behaviour matches the prescriber’s recommendations (Nunes et al., 2009).

Concordance – consultation process in which patient and prescriber agree to therapeutic decisions and includes support of patients with medication-taking and prescribing communication (Nunes et al., 2009).

Congestive Heart Failure – abnormal condition of impaired cardiac pumping. Failure of ventricles to eject blood efficiently results in volume overload, ventricular dilatation and elevated intracardiac pressure. Increased left side pressure causes pulmonary congestion; increased right side pressure causes systemic venous congestion and peripheral oedema (Harris, et al., 2006).

Cytochrome P450 – a protein involved with extramitochondrial electron transport in the liver and during drug detoxification (Harris, et al., 2006).

Factor V Leiden – mutation for Factor V making increased risk of thrombosis (Harris, et al., 2006).

Haemostasis clinic – outpatient service for Haematology Department (Healthpathways, 2011b).

Hepatic clearance – The ability of the liver to eliminate a drug as a result of metabolism. Usually by liver drug-metabolising enzymes (Bryant & Knights, 2007)

Hypercoaguability – a tendency for the blood to coagulate more rapidly than normal (Harris, et al., 2006).

Isomer – molecules that have the same molecular mass and formula but different structures, resulting in different properties (Harris, et al., 2006).

MedTech 32 – a patient management system software programme majority of practices utilise within New Zealand within Primary Healthcare (Medtech Global Ltd, 2011).

Mihi – greeting, speech of greeting (Ka'ai, Moorfield, Reilly, & Mosley, 2011).

Mitral regurgitation – a backflow of blood from the left ventricle into the left atrium in systole (Harris, et al., 2006).

Ngāi Tahu- the Māori iwi (tribe) for the majority of the South Island of New Zealand (Te Rūnanga o Ngāi Tahu, 1996).

Non-maleficance – principle of medical ethics, to minimise harm. Original Hippocratic Oath- to do no harm (Harris, et al., 2006).

Pegasus Health – not-for-profit organisation established in 1992 to support 95 practices within the Christchurch area. Supports practice teams to deliver high quality healthcare. Much of the work is funded by government through the Primary Health Organisation (Pegasus Health, 2011a).

Peripheral Vascular Disease - abnormal condition that effects the blood vessels and lymphatic vessels, except those that supply the heart (Harris, et al., 2006).

PHARMAC – Pharmaceutical Management Agency. PHARMAC interacts with Ministry of Health, Medsafe and District Health boards to provide New Zealanders with affordable access to prescription medicines, and to promote the optimal use of medicines (PHARMAC, 2008).

Plasma proteins – proteins that constitute six to seven percent of the blood plasma in the body. Proteins help maintain the water balance that effects osmotic pressure, increases blood viscosity, and helps maintain blood pressure. Plasma proteins except gamma globulins are synthesised in the liver (Harris, et al., 2006).

Primary Healthcare – Healthcare provided within a community setting from a General Practitioner or practice nurse (Ministry of Health, 2011b).

Pōwhiri – welcome, invitation, ceremonial welcome (Ryan, 1997).

Protein S deficiency – protein found in the blood and produced by the liver that is a naturally occurring anticoagulant. Deficiency leads to an increased risk of thrombosis (Harris, et al., 2006).

Teratogenic – any substance, agent or process that interferes with normal prenatal development, causing the formation of one or more developmental abnormalities of the foetus (Harris, et al., 2006).

Thrombosis – an abnormal condition in which a clot (thrombosis) develops within a blood vessel (Harris, et al., 2006).

Treaty of Waitangi –New Zealand/Aotearoa's 'founding document' (Ka'ai, et al., 2011).

Vitamin K – essential co-factor in the synthesis of blood clotting factors II, VII, IX and protein C and S. Acts as an antagonist of oral anticoagulants (Harris, et al., 2006).

Warfarin – oral anticoagulant. Prescribed for the prophylaxis and treatment of thrombosis, atrial fibrillation and embolism (Harris, et al., 2006).

Whaka-papa –genealogy, family tree, cultural identity (Ryan, 1997).

Whānau - family group, family, extended family (Ka'ai, et al., 2011).

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CHAPTER 1

INTRODUCTION/BACKGROUND

1.1 INTRODUCTION

The initiation, prescribing, monitoring and maintenance of the drug ‘Warfarin’ is an important component of Primary Healthcare (PHC) practice. Warfarin is considered to be underutilised (Hughes & Messerley, 2009), and with an ageing population, multiple medication regimens and co-morbidities (Erban, 1999), there is the possibility that usage will increase within PHC, despite the introduction of a new anticoagulant Dabigatran¹. Nurses in PHC therefore need to be cognisant of the impact Warfarin therapy has on patients’ lives.

Chapter one presents the influence of nursing theorists, family nursing, and cultural safety on my practice. The conception of this study, through intuition, experience and observation is described. The context of PHC within New Zealand (NZ) is considered, as well as implementation of PHC initiatives and how this relates to Warfarin therapy. Māori health perspectives and the difference to European health are considered, highlighting the influences of colonisation on Māori health, the burden of disease they endure, and the integration of traditional health beliefs into a Westernised health perspective. Chapter one concludes with an explanation of the structure of this thesis and what the individual chapters detail.

¹ Dabigatran is a new anticoagulant that directly inhibits thrombin and Factor Xa. Dabigatran has no prescribing restrictions from 1st July, 2011. Dabigatran is indicated for use in atrial fibrillation and post orthopaedic surgery, with information to date based on one random controlled trial. There is an increased risk of dyspepsia, gastro-intestinal haemorrhage, bleeding and myocardial infarction. Dabigatran has no antidote and poor stability, as well as requiring monitoring of creatinine clearance as it is predominately renal excreted (Burgess et al., 2011; Healthpathways, 2011a; Medsafe, 2011; Pegasus Health, 2011b; PHARMAC, 2011).

1.2 PERSONAL HISTORY AND INFLUENCES

Practising as a nurse uncovers the privilege of engaging with a diverse range of people. Initially my nursing career evolved through secondary care whereby I worked within a setting that enveloped an acute clinical area. Working in an acute medical setting and after two years at a managerial level I decided to return to clinical practice and continue my vocation in a community setting.

Primary Healthcare nursing in the community at that time largely involved nurses working as a ‘hand-maiden’ for doctors’, which I found uncomfortable within my nursing philosophy. The influences on my practice are guided personally by my absolute belief that people deserve and expect high quality healthcare, experience and service delivery. These beliefs are intrinsically linked to the way I personally practice. My practice is influenced from several viewpoints. Embarking upon a Bachelor of Nursing Degree 14 years after my original nursing qualification introduced reflective practice as a way to improve and question (Emden, 1997). By critical analysis and reflection, evolution from a passive to an active role within nursing aided self- improvement that was beneficial to my role as a nurse and to patients.

1.2.1 Cultural safety.

Within a NZ context the principles of the Treaty of Waitangi are integral to any practice arena. The principles of the Treaty of Waitangi highlight partnership, participation and protection (Wood & Schwass, 1993). The founding document from 1840 epitomises the colonisation of the indigenous people of NZ (Māori) and the inequalities that ensued. The reality is that poor Māori health in 2011 originates from the cultural, social and economic disadvantages experienced by Māori as a direct interpretation and implementation of the Treaty of Waitangi (Papps & Ramsden, 1996). Cultural safety evolved from addressing issues arising from the Treaty. The principles of cultural safety, however applies to all people, not just Maori. With nurses positioned to make a difference as often the first health professionals people come into contact with, nursing attitudes are important and are one aspect of making nursing care safe (Papps & Ramsden, 1996).

Cultural safety requires nurses to understand their own culture, their culture as a nurse and the power these can have on recipients of healthcare (Papps & Ramsden, 1996; Ramsden, 2000). Culturally unsafe practice leaves people feeling diminished, demeaned and disempowered. Cultural safety focuses nurses to assimilate respect, rights and recognition of people into their practice (Nursing Council of New Zealand, 2011; Ramsden, 2000; Wood & Schwass, 1993). Nurses are required to be mindful of their power in language, their culture and to be regardful of differences. The devolution of power to recipients of healthcare evolves to partnership, participation and empowerment. Cultural safety recognises that only recipients can verbalise if they feel culturally safe (Nursing Council of New Zealand, 2011; Papps & Ramsden, 1996; Ramsden, 2000).

1.2.2 Nursing Theorists.

My nursing practice includes partnership with patients, families and significant others as well as other health professionals and I regard relationships and caring as important. Recognition that each situation is unique, individual and personal and inclusive of cultural safety is influenced by nursing theorist Judith Christensen's Nursing Partnership Model (Christensen, 1993). The Nursing Partnership transcends all aspects of nursing and is an important component in any practice forum. Negotiation and collaboration are essential components. It also encompasses reflection on nursing practice and allows integration with nursing practice and nursing education. Its strength is the ability to adapt to any situation or context and to illuminate nurses' contribution and caring, while patients are central (Christensen, 1993).

Similarly, nursing theorist Patricia Benner regards a person's health experience as unique and related to an experience which is situated and contextual (Benner, 1994). An exploration of caring, which is central to nursing and is crucial in any healthcare practice, discusses expert nurses regarding caring as a privilege. Nursing relationships primarily encompass caring, even in adversity (Benner & Wrubel, 1989). Nursing is complex, varied and requires adaptation to changing clinical situations. Nurses utilise experiential learning and application to individual situations by ethical practice and exemplary clinical judgement (Benner, Tanner, & Chesla, 2009).

1.2.3 Family Nursing.

Inclusion of family nursing into my nursing practice evolved from post-graduate education. Family nursing is integral to PHC, with entire families being cared for. Relationships are significant and influence individual and family health (L. Wright & Leahey, 1990). Family nursing moves away from the Cartesian view dominated by the bio-medical model of health which is reductionist and uses quantification and observation (Doane & Varcoe, 2005). Family nursing incorporates a philosophy and an interpretative inquiry that is contextually embedded and uncovers the family's meanings and experiences with support (Hartrick & Lindsey, 1995). Family nursing is seen as relational practice that is collaborative and mutual. Humans are always in relationships with others and these are dynamic and changing. Family nursing looks at the person as a whole, not only their health. Relationships require an openness and respect which empowers people (Hartick, 2000).

My nursing practice therefore encompasses a philosophy that incorporates ethical comportment, sound clinical knowledge and judgement and is also influenced by nursing theorists, cultural safety and family nursing. This emphasises the importance I regard to a praxis that is inclusive of patients and valuing their perspective.

1.3 PROBLEM STATEMENT

The impetus for this study originated from clinical practice through observation, experience, reflective practice and evaluation. A problem was identified that disclosed the limited knowledge health professionals have in relation to patients' experience of Warfarin therapy. Engaging with patients who take Warfarin highlighted the complexity of this medication and the huge imposition this medication has on their lives. Not only do patients take this medication at the advice of health professionals, it has a narrow therapeutic index between sub-therapeutic and toxicity. Having involvement with fifty patients that take Warfarin in clinical practice, I began to question what influence Warfarin therapy appeared to have on them. My experience saw patients managed in PHC after being initiated on Warfarin in secondary care. The goal of a seamless transition between the primary/secondary

interface is notional, and in my experience does not exist. The service is disjointed, with patients put at risk. Patients' understanding of Warfarin after many years still appears limited. Patient education was regarded by all patients as being limited and ineffectual. My clinical practice anecdotally appeared to have a disproportionate number of Māori taking Warfarin. I began to ponder what patients' experience of this complex medication was. If health professionals understand more fully the patient's point of view, it is possible to work together to understand and assist in empowering them. My primary objective is to improve patients' care and experience.

1.4 THE IMPORTANCE OF THIS STUDY

In PHC in NZ, there are no specific national guidelines pertaining solely for the initiation, education and monitoring of people on Warfarin therapy (Geevasinga, Turner, & Mackie, 2004; New Zealand Guidelines Group (NZGG), 2003). Even though the Cardiovascular and Atrial fibrillation and Atrial flutter guidelines assist in recommendations for initiation and treatment (NZGG, 2003: 2005: 2009). Each general practice delivers monitoring and care of Warfarin differently, with nursing have a role that potentially could be developed (Geevasinga, et al., 2004). Practice nurses are positioned to manage the everyday realities of Warfarin management and work towards a collaborative, self-management and partnership model of care (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

A recent government initiative has seen a pilot of pharmacist-led point of care testing for Warfarin (Shaw, Harrison, & Harrison, 2011) which is reported as cohesive as well as divisive of a team approach (Shaw et al, 2011). The pilot could potentially erode the close relationship that has developed between the doctor, nurse and patient in regard to Warfarin monitoring and management. Additional layers of bureaucracy increases patient risk. Risk increases through fragmentation of care and involvement of numerous health professionals'. Fragmentation increases patient confusion and introduces uncertainty about responsibility between health professionals (Shaw et al, 2011). Fragmentation also introduces the possibilities of miscommunication, misinformation and knowledge deficits about medication. Alteration of Warfarin dosages by pharmacists without the PHC team's knowledge

could potentially lead to serious consequences as lack of cohesive management exposes patients to danger (Shaw et al., 2011).

My work setting is a NZ urban general practice, with a diverse client base and located in a lower socio-economic community. My observation is that nurses in PHC are required to be malleable, adapt to changing situations and are challenged to continuously and consistently deliver high quality healthcare. Nurses have the ability to instigate an individualised model of care, have involvement in co-ordination of services and work within a collaborative team (Ministry of Health (MoH), 2001). Nurses assist in and need cognisance of reducing barriers to access, especially financial, and knowledge of available funding streams support instigation of this.

Increased responsibility for Warfarin therapy is being devolved to PHC, therefore, uncovering the patient's point of view is essential to improve quality outcomes (Carryer, Budge, Hansen, & Gibbs, 2007a; Carryer, Snell, Perry, Hunt, & Blakey, 2007b). This study will assist meeting international and national objectives for PHC, where the community is responsible for its health through health promotion, collaboration, partnership and participation (MoH, 2001; World Health Organisation (WHO), 1978a, 1978b, 1986). If health professionals do not understand a patient's viewpoint, then we cannot understand how we can assist them. The purpose of this research originates from a perceived deficit of qualitative research from the patient's perspective; which could potentially reveal their perspective, understanding and give them a voice.

1.5 THE STUDY POPULATION

The study population involves patients from PHC practices within an urban setting. Research to date has included participants mainly within a hospital setting, who are elderly with atrial fibrillation (Bajorek, Ogle, Duguid, Shenfield, & Krass, 2007; Dantas, Thompson, Manson, Tracy, & Upshur, 2004). Therefore, this study aims to represent a diverse section of the population within a PHC setting. Inclusion criteria includes participants who are managed in PHC, have been taking Warfarin for longer than three months and who are over eighteen years old. Exclusion criteria include participants who are taking Warfarin temporarily and are not managed by the

PHC team. Participants from the researcher's practice are excluded to reduce bias and coercion. All medical indications for Warfarin therapy is included; although no patients were eventually recruited who currently or had previously been treated for Deep Vein Thrombosis or Pulmonary Embolus.

1.6 RESEARCH QUESTION

Reflecting and utilising the influences on my nursing practice, the research question evolved: **What is the experience of Primary Healthcare patients who take long-term Warfarin in New Zealand?**

1.7 AIMS OF THE STUDY

- To explore the PHC patients' experience of initiation, monitoring, education and management of long-term Warfarin therapy.
- To explore patients' issues, lifestyle, actions, and beliefs with respect to Warfarin therapy.
- To explore the patients' understanding of their relationship with primary care health professionals including dynamics, rapport, and decision making processes regarding Warfarin therapy.

1.8 BACKGROUND TO NEW ZEALAND HEALTHCARE

Warfarin therapy requires patients to have ongoing contact with the PHC team. Although Warfarin is mostly initiated in secondary care, it is the long-term responsibility of PHC to monitor, deliver and communicate the management of this medication. Therefore, it is necessary to understand how PHC is structured within a NZ context.

Knowledge of PHC imparts a greater understanding of the complexities and intricacies that have driven government initiatives. The Government's health objectives correlate to the PHCS which originates from the WHO recommendations (MoH, 2001). The initiatives focus on introducing funding streams, health promotion and nursing role development (MoH, 2011b). Governmental initiatives and services are administered by alignment to the PHCS which directly influences the ability of

PHC to access funding initiatives for patients. It is therefore essential these strategies and the structure of governmental agencies are understood. The MoH initiates targets for PHC to achieve; to assess that implementation of services and initiatives have been effective for patients (Francis, Chapman, Hoare, & Mills, 2008; MoH, 2011b). This requires nurses to be conscious of the social implications to practice, as well as the political influences on healthcare.

NZ healthcare system is run by the MoH, a government agency responsible for policy advice, regulation, funding and monitoring. Healthcare within NZ is publically funded for secondary care services, which equates to a 'no-cost' for hospital-based services to healthcare recipients. Primary Healthcare is unique in its distribution of funds. The government allocates funding, although approximately 60% of income for General Practitioners is obtained through patient co-payment (Francis, Chapman, Hoare, & Mills, 2008). There are twenty geographical District Health Boards. Christchurch is part of the Canterbury District Health Board (CDHB). The CDHB is responsible for allocation of funds to PHC through organisations called Primary Health Organisations (PHO). Primary Healthcare is governed by PHOs. Primary Health Organisations are non-governmental organisations that interface between the CDHB and the General Practice teams. The PHO provides funding streams for enrolled populations and assist in achieving project aims, as well as education. The PHO assists in meeting targets, based on health outcomes, instituted by MoH in accordance with initiatives they instigate. Central to the services provided by PHC is the role of health promotion as defined by the PHCS (Francis, et al., 2008).

The founding documents which guide PHC originate from the Alma-Ata Declaration in 1978 where the social determinants of health were recognised and discussed (WHO, 1978a; 1978b). The Alma Ata conference in 1978 was the first to recognise the importance of PHC and led to the World Health Organisation (WHO) developing and accepting the phrase 'Health for all'. The Ottawa Charter for Health Promotion organised by WHO in 1986 considered increasing the standard of living (WHO, 1986). The key components introduced were advocacy to encourage health, enabling to empower, increase quality of life and equity of health, as well as mediation through collaboration, not just the health sector but communities.

These founding documents were the catalyst for individual countries to incorporate these principles into their PHC models. The NZ government initially introduced the NZ Health Care Strategy (NZHCS) (MoH, 2000) to give direction to the health sector and assist to set priorities. The NZHCS supports the District Health Boards with direction and ensures co-operation, as well as improving the quality of service. The NZHCS then moved to encompass population health (Francis, et al., 2008; MoH, 2000).

The Primary Health Care Strategy (PHCS) followed on from the NZHCS and focuses on the direction of PHC in NZ (MoH, 2001). The PHCS directs a focus on inequalities of healthcare, increasing access to PHC and workforce development, to improve the health of New Zealanders (Francis, et al., 2008; MoH, 2001). The PHCS incorporated the principles of the Alma-Ata Declaration and the Ottawa Charter, of which the WHO encouraged individual countries to adapt to their context (WHO, 1978a, 1978b, 1986). The focus for implementation of the PHCS revolved around the principles of focusing on people and community; with importance placed on education and prevention and reducing inequalities in health outcomes. Teamwork was recognised as integral to its implementation with funding based on needs, and concurrently addressing the cultural competence of the workforce. Connection between health and non-health agencies was regarded as assisting its implementation (Francis, et al., 2008; MoH, 2001).

1.8.1 Funding initiatives.

The knowledge and understanding of funding streams by health professionals within PHC assists in increasing access, continuity for patients and consciousness of the increased financial outlay (MoH, 2011b). A long-term medication, such as Warfarin, is an example of a medication that requires increased visits and continuous monitoring. Funding streams that address access and reduce barriers for patients who take Warfarin are now discussed.

The MoH introduced Care Plus, a funding initiative in 2004 to assist with patients who have two or more chronic conditions, who endure the burden and disability of disease and who are a significant expense to the healthcare system;

where PHC plays an important role (MoH, 2011b). Care plus aims to improve care, reduce inequalities, increase teamwork and reduce cost for patients with high healthcare needs. Eligibility includes two or more chronic conditions, two acute medical or mental health admissions within the last six months, terminal illness, six first level PHC visits in the last six months or on active review for elective services (MoH, 2007b; 2011b; 2012). The flexible funding is managed differently throughout each PHO and each individual practice.

A further funding initiative, Services to Improve Access (SIA) addresses a key priority of the PHCS in reducing barriers to healthcare to the people that need it the most. With PHC as the first point of contact for healthcare SIA assists in increasing access. Services to Improve Access targets people that are known to have reduced health status, namely Māori, Pacific Island and people from NZ deprivation index nine to ten (MoH, 2007c). The NZ Deprivation Index (NZ Dep Index) is a rating for small geographical areas based on census information. The NZ Dep Index is the method of grading to address inequalities by the MoH recognising a social gradient for the NZ population. The NZ Dep Index is graded from one to ten. A deprivation level of nine to ten indicates higher deprivation and is associated with a poorer health status (Francis, et al., 2008; Salmond & Crampton, 2002; Salmond, Crampton, & Sutton, 1998).

The continuation of the implementation of the PHCS evolves to a recent governmental initiative of 'Better, Sooner, More Convenient' (Ryall, 2007) which represents improving PHC through an integration of health services within a geographical area. Consequently, people have easy access and PHC is reflective of individual needs as well as the needs of the community. Governmental expectation is that this will reduce pressure on hospitals and reinstitute PHC as essential and integral to the health of New Zealanders (MoH, 2011b). The implementation at a local level within Christchurch has formulated in the development of the Canterbury Clinical Network which is a group of multidisciplinary community providers. Canterbury Clinical Network collaborates with the CDHB to address regionally how this will be implemented; addressing the health needs, goals and funding of the local community (Canterbury Clinical Network, 2011).

1.8.2 Māori Health.

Māori perspectives on health differs from Westernised cultures and needs consideration, integration, understanding and respect from professionals that deliver healthcare (Durie, 1985). Poor Māori health today is a direct response to the colonial history that has marginalised and transferred power away from Māori, which resulted in their norm becoming altered (Reid & Robson, 2007). The disparity in health statistics is indicative of the burden of disease, which is disproportionately represented by Māori and has led to increased morbidity and mortality compared to non-Māori (Ajwani et al., 2003; NZGG, 2003). Therefore, understanding the Māori healthcare belief is essential with Warfarin therapy.

Māori health incorporates a holistic and cyclical perspective where every person is linked to everything. This links customs and concepts which is necessary to understand Māori health (Ka'ai & Higgins, 2011). The basic tenets of Māori health consider four concepts, which are all essential for health and well-being and if one of these tenets is missing, this leads to an imbalance and a person becomes unwell. Whare Tapa Whā is one Māori health model that has been adapted to explain these concepts (Durie, 1985; MoH, 2011a; Rochford, 2004). The concepts are firstly spiritual health (Te taha wairua) which is essential for well-being; it is the life-force which incorporates where we are from and where we are going. Mental health is second (Te taha hinengaro) and is holistic where communication is essential; thoughts and feelings are fundamental for health. Physical Health (Te taha tinana) is third and regarded as central to development. Finally, family health (Te taha whānau) extends to the wider social context. The family (whānau) provides strength and links to ancestors, the present and future (Durie, 1985; MoH, 2011a; Rochford, 2004).

The introduction of the He Korowai Oranga: Māori Health Strategy to NZ (MoH, 2002) aligns with the principles of the Ottawa Charter for Health Promotion (Rochford, 2004; WHO, 1986). Māori health is recognised by the integration of the Ottawa Charter and the principles of the Treaty of Waitangi which utilises partnership, protection and participation for the foundation of healthcare (Rochford, 2004). Mauri is the spiritual and physical relationship which describes the life-force which cannot be weakened and is the key to health. Whaka-papa explains that Māori

are not just joined to land as an integral part of nature, they are in a relationship with every living thing (Ka'ai & Higgins, 2011; Williams, 2011). Mauri is an important concept when taking blood from patients who identify as Māori, with their belief regarding blood as sacred. Awareness of this is crucial when working with Māori patients on Warfarin.

1.9 STRUCTURE OF THESIS

The development of the research question and the background of the thesis has been explained throughout Chapter one. It has explained the reasons why this research will add to current knowledge. A background to PHC within a NZ context introduced key government documents and initiatives. Governmental documents and initiatives underpin the provision of healthcare within NZ PHC and the recognition of the nurses' role. Chapter one has introduced the researcher and the influences that impact on practice and the personal development and journey that results in this thesis.

Chapter two discusses literature, commencing with cardiovascular disease statistics, the indications for Warfarin therapy, proceeding to how this medication plays a part in daily lives. Literature regarding lay beliefs and myths about Warfarin will be highlighted. How Warfarin therapy relates to PHC, the relationships with health professionals and the role of the nurse will be examined. Chapter two concludes by explaining the paucity of qualitative literature.

Chapter three describes the methodology underpinning this research. A qualitative inductive approach utilising Thomas' (2003) framework is discussed. The rationale for utilising this approach will be considered and the researcher's decision trail to demonstrate the considerations of ethical research, and enhancement of rigour, trustworthiness, confidentiality and validity.

The next chapter, Chapter four, presents the analysis and findings. Utilising inductive content analysis, the findings include six key themes which are interrelated, but presented separately in order to discuss themes logically. The themes are:

1. Impact.
- 1.2. Self.
- 1.3. Knowledge acquisition.
- 1.4. Information/misinformation.
- 1.5. Education.
- 1.6. Relationships with health professionals.

The themes are further divided into categories and sub-themes. Each category, sub-theme and theme will be explained with excerpts from transcripts to support the findings.

Chapter five discusses the interpretation of the findings, commencing with a discussion of the six themes integrated with literature and what this means to practice. Following on from this is a discussion of the limitations and strengths of this study.

In conclusion, Chapter six discusses the relevance of this research to practice, linking the aims of this research and concluding with the implications for practice and suggestions for future research.

1.10 CONCLUSION

The outline of the researcher's influences as a nurse and the impetus for the origins of this study has been discussed in this chapter. The effect of two nursing theorists, family nursing and cultural safety that directs nursing and shaped this research has been discussed. The integration of key documents and initiatives that guide PHC, originating from the Alma-Ata declaration and the Ottawa Charter for health promotion have been described within PHC in NZ. The key concepts of Māori world view revealed not only the disparities, but the differences in health beliefs. The history of colonisation has marginalised Māori health perspectives. An awareness of the Māori perspective is essential for health professionals with Warfarin therapy and their beliefs and values regarding blood. The aims of the study have been outlined. This chapter concluded with reviewing the layout of this thesis

and what each chapter entails. The following chapter, Chapter two will review the literature.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Warfarin is a medication that practice nurses deal with daily. Through observation in the clinical setting, it has been highlighted that patients have ongoing difficulties in adhering to Warfarin medication regimens. The NZGG (2005) state there is a lack of co-ordinated education regarding Warfarin within PHC in NZ. Warfarin has a narrow therapeutic index and requires careful dosing and frequent monitoring. There are potentially serious side-effects (Hirsh et al., 2001) which reflect the need for well-informed patients. Patients in NZ are mostly initiated on Warfarin therapy in hospital, with minimal initial education and then discharged into PHC (NZGG, 2005).

There are recommendations for the initiation of Warfarin in the NZ Cardiovascular Guidelines and Management of people with Atrial Fibrillation and Atrial Flutter (NZGG, 2005, 2009), as well as international guidelines (British Columbia MoH, 2010; Keeling et al., 2011). There are however no Warfarin-specific national standardised guidelines for education and monitoring of Warfarin (Geevasinga, et al., 2004). Each District Health Board has their own protocols for initiation. There is a deficit, and a requirement for a Warfarin-specific standardised protocol nationally to be introduced (NZGG, 2005) and developed. Through observation in clinical practice, there currently appears to be ad-hoc education within PHC and diverse differences in dissemination of information to patients, from general practice to general practice and practitioner to practitioner. Inconsistency, of which guidelines are utilised, if any, therefore could potentiate problems.

Internationally it is recognised that Warfarin is underutilised in a large percentage of the population (Hughes & Messerley, 2009; NZGG 2005). The initiation of Warfarin is on a case-by-case decision between doctor and patient with

close consideration of clinical indications and risks for bleeding (Gallus, 1999). Warfarin is identified as a high risk medication with the potential for adverse side-effects which requires frequent monitoring and patient compliance (Hughes and Messerley, 2009). On initiation of Warfarin a discussion needs to be undertaken whereby the risks versus the benefit of Warfarin is analysed and discussed with the patient (Erban, 1999). There are numerous tools to assist in the decision-making process. NZGG (2005 & 2009) utilises stroke risk assessment to assist in decision-making and Pisters et al. (2010) applies the HAS-BLED scoring system. These tools assist in deciphering if the risk of potential bleeding outweigh the benefit of stroke prevention or clot formation (Hughes & Lip, 2007). Despite this, elderly patients are increasingly prescribed Warfarin in conjunction with multiple co-morbidities and poly-pharmacy (Erban, 1999) which impact on the complexity of Warfarin management. Deliberation and interest for this thesis evolved from how this medication impacts on patients and what issues are relevant from a patient point of view.

The aim of this literature review is to give a scholarly basis to the research question: **What is the experience of Primary Healthcare patients who take long-term Warfarin in New Zealand?** The literature review will commence by discussing the statistics internationally and nationally for cardiovascular disease (CVD). It will then proceed to discuss where Warfarin is situated in the treatment of CVD, followed by the development of Warfarin, its use as a rat poison and the myths associated with this. Warfarin as a medication, will be discussed and subsequently the interactions with diet, medication and complementary medication. Following will be a review of the literature retrieved, highlighting literacy, education, self-management or clinic-management. Primary Healthcare in NZ will be examined, how it works, relationships with health professionals, long-term medication-taking in chronic illness and the practice nurses' role with Warfarin management. Finally, literature from a qualitative perspective will be reviewed, concluding with two recent pieces of literature retrieved on completion of interviews pertaining to the patients' experience of Warfarin.

2.2 SEARCH STRATEGY

The search strategy for relevant literature commenced with searching databases. Databases utilised were Cinahl, Ovid, Up-to-date, Medline, Pubmed, Google Scholar and Cochrane. The Trip and Bandolier websites were also accessed. The exclusion criteria for articles were non-English language, not human research, grey literature, no full-text or PDF available and articles pre January 1990. Inclusion criteria were peer-reviewed journals and research articles with a high impact factor and ethical approval.

The following search terms were used in each database. Text word, truncation and Boolean searches were used for each search term. Firstly, the 'patient's experience' of Warfarin with combinations of the following words was sequentially searched using 'Warfarin and ...'; diet, medication, compliance, non-compliance, advantages, disadvantages and quality of life. The search then proceeded to other key words noted during earlier searches; Warfarin, INR, concordance, adherence, non-adherence, education, knowledge, understanding, attitudes, behaviour, autonomy, satisfaction, quality of life, primary care, community, family physician, self-management, point-of-care, and lifestyle. These key words were sequentially searched as well as combined with the word 'Warfarin'.

The initial search rendered 37 872 articles, but as each key word was combined, this significantly reduced the amount of data retrieved. As the scope was too broad, it was necessary to restrict the search. Significant words were developed as articles were retrieved and recurrent themes emerged. The literature search required a broader scope to encompass patients' pharmacological beliefs and taking medication long-term. There was no literature specific to patients' experience of Warfarin; therefore literature with parallels to other long-term conditions in which alternative medications was needed. Words searched within this context included diabetes, arthritis and 'rat poison'. Eventually there was repetition of articles on differing databases, and citations in reference lists.

Several journals thought to be relevant were specifically searched using the same key words. These journals were Journal of Advanced Nursing, Nursing Praxis,

Qualitative Health Research, British Medical Journal, the Best Practice Journal, NZ Family Physician and Journal of Primary Healthcare. The reference list of all articles retrieved were also utilised to access primary sources and further relevant articles.

The NZ Cardiovascular Guidelines Handbook: A Summary Resource for Primary Care Practitioners (NZGG, 2009), Management of People with Atrial Fibrillation and Atrial Flutter (NZGG, 2005); Assessment and Management of Cardiovascular Risk (NZGG, 2003) were analysed and articles retrieved. The number of articles retrieved was 195. After analysis, the final number of articles utilised for inclusion in the literature review was ninety-seven.

2.3 CARDIOVASCULAR DISEASE

Cardiovascular disease (CVD) is grouped into disorders of the heart and blood vessels and includes; coronary heart disease (CHD), cerebro-vascular disease, rheumatic heart disease, congenital heart disease and peripheral vascular disease (PVD) (WHO, 2011a, 2011b). CVD is a global problem and affects all ethnicities (Yusuf, Reddy, Ounpuu, & Anand, 2001). High rates of CVD are disproportionately represented in people of low socioeconomic status, certain ethnic groups and geographical location (Cooper et al., 2000).

2.3.1 Cardiovascular disease internationally.

Cardiovascular disease was the third most common cause of death internationally in 1999. In 2004 it became the leading cause of death (WHO, 2011a). CVD occurs equally between men and women. However, there are a disproportionate number of deaths in low to middle income countries (WHO, 2011b), thereby increasing the burden of disease. The number of CVD deaths is 17.1 million a year, accounting for 29% of all deaths internationally per year. By 2030, the death rate from CVD is predicted to reach 23.6 million (WHO, 2011b).

Cardiovascular disease resulting in atrial fibrillation increases the risk of a cerebro-vascular accident (CVA) by five times (WHO, 2011a). Every six seconds a person will die from a CVA independently of age or gender (World Stroke

Organisation, 2011). Of the 15 million suffering a CVA, this includes five million who will die, and five million who are left disabled (WHO, 2011b).

In the United States of America (USA), CVD is responsible for 33.6% of all deaths. The prevalence of some form of CVD in people is 33%, with half occurring in over sixty year olds (Roger et al., 2011). The incidence of a first CVD event from 1980 to 2003 is; 3 per 1000 for people aged 35 – 44 years; the incidence increases to 74 per 1000 for people over 85 years, with women able to be compared to men ten years later (Roger, et al., 2011). Men have a higher incidence of CHD than women, but women have a higher incidence of CVA (Roger, et al., 2011). The American Heart Association goals to 2020 are to reduce the death rate from CVD and CVA by 20% (Lloyd-Jones et al., 2010).

2.3.2 Cardiovascular Disease in New Zealand.

CVD is divided into CHD and cerebro-vascular disease in the NZ health statistics. CVD accounts for 40% of all deaths, with 30% attributed to CHD (Hay, 2004; NZGG, 2003). Although more men die from CHD than women, in the case of cerebro-vascular disease they are equal. Sixteen New Zealanders die each day from CHD, which equates to one person every 90 minutes (Hay, 2004).

Since 1970 there has been a reduction in mortality due to CVD for both men and women in NZ. In 2000, CHD death rates are disproportionately higher in Māori than non- Māori, with Māori women exhibiting worse outcomes than men (Curtis, Harwood, & Riddell, 2007; Hay, 2004). Specific ethnicities bear an increased burden of CHD, with increase in incidence and mortality in Māori and Pacific Island communities (Hay, 2004; NZGG, 2003, 2005). There has been a decline of CHD in Māori men over the last 15 years. Conversely, there has been an increase in Māori women and an increase in Pacific Island men and women (Hay, 2004).

Cerebro-vascular accidents are the second most common cause of death in NZ. There are 6000 people per year affected by a CVA, with 2000 dying (Stroke Foundation of New Zealand (SFNZ) & New Zealand Guidelines Group (NZGG), 2010). Disability from CVA is a major health burden. The NZ European population has a reduced incidence of CVA. The NZ Māori population has no reduction and the

Pacific Island population has an increased incidence (SFNZ & NZGG, 2010) highlighting a significant disparity within the CVA statistics. Māori experience CVA younger, at 61, compared to NZ European at 76 years of age (SFNZ & NZGG, 2010).

2.4 WARFARIN AND CARDIOVASCULAR DISEASE

2.4.1 Indications for use.

Warfarin is indicated to reduce the risk of CVA caused by venous or arterial thrombosis (Freedman, 1992; Gallus, 1999). Warfarin does not dissolve pre-existing clots, but prevents further deep vein thrombosis or pulmonary embolism (Bryant & Knights, 2007; Campbell et al., 2001; Erban, 1999; Freedman, 1992; Gallus, 1999). Warfarin reduces the risk of CVA in atrial fibrillation, post myocardial infarction, or post-embolic CVA (Campbell, et al., 2001; Erban, 1999; Freedman, 1992; NZGG, 2003, 2005, 2009; Ranta, 2010). There is a distinction between atrial fibrillation caused by valvular or non-valvular disease (O'Connell & Gray, 1996). Warfarin is essential for patients with prosthetic heart valves (Campbell, et al., 2001; Erban, 1999; Freedman, 1992; Gallus, 1999; Maling & Burgess, 2006), to reduce risk and prevention of thrombo-embolism.

Utilisation of Warfarin with patients with hyper-coaguable states prevents thrombosis, these are; antiphospholipid syndrome (Horner, Phillips, Newkirk, McDanel, & Kaboli, 2008), and Factor V Leiden and Protein-S deficiency (Freedman, 1992). Use of Warfarin in PVD is contradictory. Hirsh et al. (2003) supports Warfarin usage in PVD. Campbell et al. (2001) disagrees, maintaining that there is not enough evidence to support its usage. Campbell et al. (2001) are unconvinced by Warfarin usage with congestive heart failure; conversely, Gallus (1999) regards its usage as fundamental.

2.5 INTERNATIONAL NORMALISED RATIO

The International Normalised Ratio (INR) is a laboratory test to measure clotting time. The WHO developed an internationally standardised method of measuring clotting levels to give inter-laboratory consistent results (Clarke, Ross, Walker, & Woods, 2006; WHO, 2006). This ensures each test result is reliable

(WHO, 2006). Warfarin has a narrow therapeutic window (Blann, Fitzmaurice, & Lip, 2003; Geevasinga, et al., 2004); (a small range between sub-therapeutic to toxicity) which is why a consistent and reliable monitoring test is mandatory (Blann, et al., 2003; Campbell, et al., 2001). Regular monitoring assists patients to maintain control of INR by adjusting the dose of Warfarin related to the blood test results (Best Practice, 2010).

Adverse events may be avoided with regular INR monitoring (Blann, et al., 2003; Campbell, et al., 2001) although interpretation of INR is also required (Best Practice, 2010). Warfarin is complex pharmacologically and interacts with many medications, diet, and herbal preparations; causing numerous unpredictable interactions (Campbell, et al., 2001; Waterman et al., 2004). An individual approach to monitoring of INR is required, with many individual variables effecting INR recordings. Waterman et al. (2004) examined non-adherence effect on INR and concluded non-adherence is increased with complex Warfarin regimens. The very young, elderly, men, non-Caucasian, and people with no history of previous CVA, were more likely to be non-adherent (Waterman et al., 2004).

Risks associated with Warfarin, with under and overdosing, the narrow therapeutic window and interactions with diet and medication necessitate frequent monitoring. Warfarin is beneficial, although it is the most common prescription medication to cause adverse events and death (Campbell, et al., 2001). As INR increases, so does the bleeding risk. If INR has been stable and patients are low bleeding risk, with no interacting medications, it is cautiously advised that INR can be measured every four to six weeks (Campbell, et al., 2001; Clarke, et al., 2006). Lidstone, Janes and Stross (2000) contradict this and examine longer intervals between INR monitoring. They arbitrarily utilised fourteen weeks as their time interval and conclude that patient safety was not compromised, while more cost effective and convenient to patients. Participants in this study were more likely to have had previously stable INR, therefore extending the interval between testing was not perceived as perilous (Lidstone, Janes, & Stross, 2000). Bann et al. (2003) discuss the British Haematology Society guidelines suggestion of extending INR monitoring up to a maximum of twelve weeks. Although provocatively advising safety in an extension of INR testing, the majority of authors are in agreement that

this length of time between testing would be contradictory to patient safety and clinician's best practice (Campbell, et al., 2001; Clarke, et al., 2006).

The monitoring of INR is seen as labour intensive and requires a team approach. The cost of care can be a burden on general practice and patients (Best Practice, 2010; Clarke, et al., 2006; Geevasinga, et al., 2004). Monitoring of INR could potentially take place within a variety of settings, from hospital clinics to PHC, laboratory testing to self-monitoring. The evaluation and interpretation of INR results requires knowledge of individual patients, knowledge of concurrent medications and interactions, as well as indications for Warfarin and pre-existing co-morbidities (Best Practice, 2010; Blann, et al., 2003; Campbell, et al., 2001; Clarke, et al., 2006).

2.6 DEVELOPMENT OF WARFARIN

The genesis of Warfarin as a drug therapy originated in 1920's in North America and Canada after healthy cattle were found to be dying through internal haemorrhaging (Pirmohamed, 2006; Wardrop & Keeling, 2008). Further investigation found no link to pathogens or nutritional deficits. The cause was traced to sweet clover hay that when damp, was infected by mould. The hay was usually discarded, however, during The Great Depression farmers could not afford supplementary feeds, so used the hay (Wardrop & Keeling, 2008). There are discrepancies in the literature as to the initial founder. Pirmohamed (2006) states it was Roderick. Conversely, Freedman (1992) purports Schofield, a veterinarian to have made the discovery and Wardrop and Keeling (2006) state it was Carslon. Nevertheless, Karl Link is recognised as the scientist who isolated the active compound in sweet clover hay, which he named 4 – hydroxycoumarin, but later he changed to dicumarol (Kresge, Simoni, & Hill, 2005; Pirmohamed, 2006; Wardrop & Keeling, 2008). Link later found a correlation between dicumarol and Vitamin K in relation to haemorrhaging (Kresge, et al., 2005).

The Wisconsin Alumni Research Fund (WARF) sponsored research and is where the Warfarin name originates from (Pirmohamed, 2006; Wardrop & Keeling, 2008). Stahmann, a student of Link took over the research and patented a compound

that Link thought too toxic, this was Warfarin (Kresge, et al., 2005; Wardrop & Keeling, 2008).

2.6.1 Rat poison.

Warfarin was initially applied clinically to rats. Its usage was as a rodenticide, and caused rats to die from internal haemorrhaging. This application is still currently utilised (Freedman, 1992; Kresge, et al., 2005; Wardrop & Keeling, 2008). The clinical application of Warfarin for humans was developed and introduced in the late 1940s and in 1950 it was administered to President Dwight Eisenhower (Kresge, et al., 2005; Wardrop & Keeling, 2008). However, Wardrop and Keeling (2008) discuss that the first clinical trials involving Warfarin did not commence until 1960.

3.6.2 Myths/Lay beliefs.

There appears to be a paucity of literature about people's beliefs and myths regarding 'rat poison' as a medication. Hence, an ability to parallel this concept to medication-taking and lay beliefs on other medication is vital.

Patients' beliefs and perceptions play an important role in regard to medication-taking. Misconceptions abound regarding a relationship between the number of prescribed medications and patient adherence (Basco, 2008; Kumar et al., 2011). Patients do not always hold similar views on medications to that of their doctors which can cause tension between conforming and self-management (Britten, 1994). Basco (2008) discusses a psychologist's standpoint, regarding patients' ability to be adherent if treatment is manageable, acceptable and understandable. Conversely, increased knowledge and education regarding medication did not change beliefs and consequently adherence in studies by Britten (1994) and Neame and Hammond (2005).

Linking use of medication to chronic conditions and taking Warfarin long-term is examined in a qualitative study exploring lay beliefs (Webster, Douglas, & Lewis, 2009). This study highlights patients' awareness of Warfarin being known as 'rat poison', its link to a toxic chemical and an agent to kill vermin. However this was not a deterrent to taking Warfarin. Key findings included value judgements on

medication by patients that included safety, efficacy and side-effects. Safety, reassurance and confidence are enhanced if relatives or friends had taken it. Safety was viewed as a social construct, not in relation to side-effects or the toxicology of the drug (Webster, et al., 2009). Britten (1994) concurs that decision-making regarding medication is socially constructed and determined by the interference of social roles of sport, leisure and work performance.

Patients' decision-making processes underlying medication-taking are complex (Kumar, et al., 2011; Neame & Hammond, 2005) and prior thoughts that socio-demographic factors influence medication beliefs have been dispelled by Neame and Hammond (2005). Patients are regarded as having good intentions towards medication, but may be overwhelmed with the introduction of new medication compounded by information deficits. Misunderstanding, lack of recollection of information, and inappropriate formation of patients' own medication beliefs encourage non-adherence. Information deficit may be filled by family and friends, adding to existing beliefs and impacting on concerns (Webster, et al., 2009). The introduction of a new medication increases the need for information, which may not be apparent at initiation (Barber, Parsons, Clifford, Darracott, & Horne, 2004).

Basco (2008) highlights misconceptions that patients are regarded as being compliant or non-compliant. Basco (2004) refutes this as a variance in a person's organisational skills and self-discipline, which emphasizes individual variation. Patients may be overwhelmed and find difficulty maintaining long-term treatment. The differences between beliefs from people of other cultures have been incorporated into a study to highlight their perception. Including food, religious beliefs, traditional medicine usage and language barriers, to thorough explanations regarding disease processes, and medication education (Kumar, et al., 2011).

2.7 WARFARIN THE MEDICATION

Warfarin was first introduced to humans forty years ago. However, the understanding of its metabolism has only recently been partially achieved (Kaminsky & Zhang, 1997). Warfarin has optical isomers S and R, with S-Warfarin five to six times more potent than R-Warfarin (Freedman, 1992; Harrison, 2008; Hirsh, et al.,

2001). Warfarin does not act directly on any pre-existing clot, although it prevents any further clot formation with its mechanism of action (Sweetman, 2005). Vitamin K is utilised by the body to produce enzymes that allow the body to stimulate clotting (Harrison, 2008). Warfarin competitively inhibits Vitamin K, thereby slowing down clotting time (Maling & Burgess, 2006).

2.7.1 Medication Interactions.

Medication interactions are common with Warfarin. The liver enzymes cytochrome P450 (CYP) are responsible for metabolising many medications. They are also responsible for catalysing Warfarin S and R isomers into metabolites (Kaminsky & Zhang, 1997).

Drug interactions with Warfarin are too numerous for clinicians to utilise a comprehensive list which could assist with prescribing. It is essential that INR levels are carefully monitored whenever there is an addition or deletion of any medication. Aids and mnemonics to assist in remembering drug interactions are quickly out of date and too numerous to remember (Feldstein et al., 2006; Freedman, 1992; Harrison, 2008; Hirsh, et al., 2001). Hirsh et al. (2001) discuss several studies of Warfarin drug interactions. All concur expertise from clinicians regarding interactions is essential as drug interactions are too numerous to list. Every medication needs scrutiny for potential interactions (Erban, 1999; Feldstein, et al., 2006; Freedman, 1992; Harrison, 2008; Hirsh, et al., 2001).

The interaction of Warfarin with other medication is multifaceted. Freedman (1992) explains the displacement from plasma proteins, the interference of absorption of Warfarin by co-prescribing of other medications, the alteration of bioavailability of Vitamin K and the direct effect on the metabolism. Harrison (2008) agrees and adds that there may be an increase in hepatic clearance of Warfarin by other medication, an interruption of the Vitamin K cycle, alteration of the gastrointestinal tract as well as an alteration of platelet function.

Personal variation is influential in drug interactions, with potential increase of interactions in the elderly. Older people are more likely to have co-morbidities, and poly-pharmacy (Erban, 1999; Ranta, 2010). Hirsh et al. (2001) explains in detail

the effect illness can have on changes to Warfarin metabolism and the association with co-morbidities and prescribed medications. Warfarin is continued to be underutilised in the elderly, although age alone is not seen as a contraindication. However, due consideration to compliance, risk of stroke versus haemorrhage, co-morbidities and concurrent medications, as well as the increased likelihood of renal and/or liver impairment and changes to cognition are essential (Ranta, 2010).

Decisions to commence Warfarin are complex, and are made on an individual basis considering risks and benefits. Feldstein et al. (2006) studied the utilisation of computer software alerts to reduce Warfarin medication interactions. Feldstein et al. (2006) highlight the increase of co-prescribing that occurs in the community. One third of all patients are co-prescribed medications that interact with Warfarin. Some medications had potentially severe interactions and exacerbated the risk of bleeding. Feldstein et al. (2006) concluded that alerts on prescribing software did assist in reducing mortality and morbidity. Although conversely, prescribers could become overwhelmed with alerts, which could potentially lead to alert fatigue and complacency. There was acknowledgement that medications with known interactions were occasionally co-prescribed with Warfarin as they necessitated management of co-morbidities. Concern regarding incomplete medication records was recognized as over-the-counter medications would not be documented on this software (Feldstein, et al., 2006).

2.7.2 Dietary Interactions.

Dietary intake of Vitamin K has a direct influence on variance of INR measurement. The need for patients to be aware of foods containing Vitamin K is essential, as this directly correlates to alterations in INR (Rombouts, Rosendaal, & van der Meer, 2010). It is recognised that the dietary intake of Vitamin K could be problematic in regulating consistent INR (Best Practice, 2007; Harrison, 2008; Holbrook et al., 2005). Vitamin K in green leafy vegetables is known to reduce the effectiveness of Warfarin (Greenblatt & von Moltke, 2005; Harrison, 2008; Holbrook, et al., 2005; Rombouts, et al., 2010).

Other dietary influences are discussed by separate authors but with no comparison. Greenblatt and von Moltke (2005) discuss vegetable oils changing

Vitamin K levels. However, Holbrook et al. (2005) regards vegetable oils changing Vitamin K levels as 'highly probable'. Some fruits and juices were documented by Best Practice (2007) and Holbrook, et al. (2005) as influencing Vitamin K, but there were no explanation as to the mechanism. Cranberry juice was noted to inhibit the metabolism of Warfarin (Best Practice, 2007; Holbrook, et al., 2005). Anecdotally, possible serious interactions with cranberry juice have been reported (Suvarna, Pirmohamed, & Henderson, 2003). However this does not appear to be substantiated with any robust measures; with influences of co-morbidities and external factors. Ansell, McDonough, Zhao, Harmatz, and Greenblatt (2009) contradict this, extrapolating cranberry's influence as insignificant. Food supplements were regarded as altering INR levels after ingestion, although explanation of what this entailed was not specified. Enteral feeds contain high levels of Vitamin K, therefore directly reducing Warfarin effect (Best Practice, 2007; Harrison, 2008).

Vitamin K concentration varies greatly in food. This variance highlights the difficulty in maintaining a constant Vitamin K serum level. Differences were also attributed to laboratories not using a standardised approach to report Vitamin K levels in specific foods, therefore adding to confusion (Rombouts, et al., 2010). Although not looking at specific foods, their study looked at the influence of dietary Vitamin K. They concluded that patients with low Vitamin K intake were more likely to be less than fifty years old and female. There was a direct correlation between dietary Vitamin K intake and fluctuations of INR results, with unstable patients exhibiting low dietary Vitamin K. Vitamin K content of food customary to specific populations or cultures is needed to enable management of Warfarin (Rombouts, et al., 2010).

Patient education regarding Vitamin K containing food is seen as important and essential (Greenblatt & von Moltke, 2005; Rombouts, et al., 2010) There are individual differences in reactions to dietary Vitamin K (Greenblatt & von Moltke, 2005). Nutritional deficiency, poor oral intake, changes to intestinal environment, physical frailty and starvation all influence dietary effects of Warfarin. Maintaining a consistent level of oral Vitamin K was regarded as the best ability to ensure stability of INR (Greenblatt & von Moltke, 2005; Rombouts, et al., 2010).

2.7.3 Complementary Medicine Interactions.

Warfarin interacts with numerous herbal and complementary medicines. Internationally the use of alternative medicines is increasing, predominantly herbal medicines (Ramsay, Kenny, Davies, & Patel, 2005). The introduction of Warfarin and the concomitant use of complementary or herbal medicines has the potential for adverse and serious consequences, including bleeding, intracranial haemorrhage and death (Feldstein, et al., 2006; Ramsay, et al., 2005; Smith, Ernst, Ewings, Myers, & Smith, 2004).

Patients admit to the utilisation of herbal medications which are known to interact with Warfarin, although patients do not necessarily notify their health provider (Smith, et al., 2004). There appears to be a misconception that herbal medication is safe and regarded as 'natural', so therefore does not interfere with conventional or prescribed medications (Ramsay, et al., 2005; Smith, et al., 2004). Ramsay et al. (2005) and Smith et al. (2004) agree that it is patient's responsibility to advise doctors of their usage of complementary medicine, as well as healthcare provider's responsibility to ask if patients are using these products. Ramsay et al. (2005) and Smith et al. (2004) disagree with the types of usage of these products. Smith et al. (2004) regard herbal medicine as the most common utilisation of complementary therapy. Whereas Ramsay et al. (2005) regards Vitamin E and fish oils as the most consumed. Ramsay et al. (2005) also see factors of general well-being, diet, daily alcohol intake, concurrent medication and age as influential in Warfarin management.

A full medication history is essential with patients who take Warfarin. It is important a full drug history is taken by health professionals, whether in primary or secondary care. Patients need to divulge all medications taken, both conventional and complementary. Smith et al. (2004) highlight the potential for adverse reactions and acknowledge this area has been under-researched. There is a need for an unbiased and non-judgemental approach to complementary medicine from health practitioners, to ensure honest discussion regarding all potential interactions. The deficiencies of computer prescription systems, which do not record herbal or complementary medicines on the database, therefore adding to potential interactions

which aggravate a lack of cohesive, accessible and up-to-date medication history (Smith, et al., 2004).

2.7.4 Smoking.

Smoking cessation continues to be an important health message to all people, not only for patients who take Warfarin. The advice to stop smoking encompasses all threads of society with health benefits being immediate, as continued smoking exacerbates disease processes (MoH, 2007a; NZGG, 2003). Health promotion sees smoking cessation improving health outcomes. Associated with heart disease, smoking cessation establishes patients' ability to halve their chance of mortality at all ages (NZGG, 2003, 2009).

Smoking has an effect on INR control. Smoking is only problematic if patients are commencing or ceasing smoking as this causes fluctuations in INR stability (Harrison, 2008). Inhaled substances in cigarettes are metabolised through liver enzymes. Metabolism of Warfarin is induced in smokers (Harrison, 2008; Holbrook, et al., 2005) thereby lowering INR's. With initiation and cessation of smoking, inhibition or inducement of liver enzymes cause fluctuations in INR, and patients may experience inadequate control (Harrison, 2008).

2.7.5 Alcohol.

Anticoagulant control varies with alcohol consumption, and researchers disagree as to the effect alcohol has on this control. Alcohol is stated to have no effect on INR with patients who have a small to moderate amount of alcohol (Campbell, et al., 2001; Harrison, 2008) and control is noted to change with varying alcohol consumption (Best Practice, 2007). Alcohol is metabolised through the liver CYP450 enzymes with chronic alcoholism inducing liver enzymes and reducing Warfarin effect (Harrison, 2008; Hirsh, et al., 2001). However, binge drinking antagonistically inhibits liver enzymes and elevates INR. Holbrook et al. (2005) agree, and add that significant interactions occur with Warfarin and concurrent liver disease. High alcohol consumption is often associated with poor diet, liver damage (Best Practice, 2007; Campbell, et al., 2001), gastritis, poor compliance and increased risk of bleeding (Campbell, et al., 2001) which complicates management and safety. Consequently cognisance of alcohol intake is essential.

2.7.6 Complications.

Warfarin is beneficial to patients for stroke prevention, although dichotomously there is a risk associated with the potential to haemorrhage. In some instances literature agrees that the risk versus the benefit needs to be calculated on an individual basis in regard to stroke prevention or potential risk of haemorrhage (Dudley, 2001; Fang et al., 2007; Ranta, 2010; Westaway, Cruickshank, Roberts, & Esterman, 2010). The complexity of prescribing Warfarin is assisted by the NZGG (2009) which shows the relative benefit versus harm when comparing Aspirin and Warfarin and the documented increased benefit but also increased risk with Warfarin. Dudley (2001) discusses the risks and benefits and the importance of communication between health professionals and patients. Dudley (2001) also examines the paternalism and manipulation exhibited by hospital doctors, influencing patients' decisions. Partnership and individualised care is seen to improve health outcomes for patients.

The potential for death and disability in patients who take Warfarin is a reality. Complications from extra-cranial haemorrhage are less likely to cause disability. Although intracranial haemorrhage is rare, it is associated with increased death, disability and an increased likelihood to cause functional deficits (Fang, et al., 2007). The risk of haemorrhage increases in the first three months of anticoagulant treatment (Campbell, et al., 2001; Ranta, 2010; Westaway, et al., 2010).

Tools have been developed to assist in assessment of bleeding risk. A large study in Europe developed the tool 'HAS-BLED' which indicates criteria for assessment of bleeding risk prior to initiation of Warfarin. The tool is easy, practical, individual and supports clinical decision-making (Pisters et al., 2010; Ranta, 2010). Ranta (2010) considers this tool to be rapid, simple and acknowledges the dilemma in the need for anticoagulation by reducing the risk of stroke and the benefit and protection Warfarin provides despite the potential for haemorrhage.

Warfarin is teratogenic. There is concern regarding the prescribing of this medication to women of childbearing age. This requires meticulous counselling and education to ensure careful management (Campbell, et al., 2001). The first trimester is particularly important with significant abnormalities reported. Avoidance of

Warfarin throughout pregnancy is recommended (Hirsh, Fuster, Ansell, & Halperin, 2003).

2.8 IMPROVING OUTCOMES

Warfarin therapy requires a collaborative approach whereby health professionals and patients work together. The following themes emerged from the literature and addresses positions that potentially could disempower and demean patients, however may also empower and represent autonomy and self-efficacy.

2.8.1 Literacy.

Health literacy was initially defined as the ability of patients to decipher the education they receive as part of their ongoing Warfarin therapy (Fang, Panguluri, Machtinger, & Schillinger, 2009). However, others view this as an ability to comprehend educational material given to patients to support their ongoing long-term Warfarin management (Estrada, Hryniewicz, Higgs, Collins, & Byrd, 2000; Wilson, Racine, Tekieli, & Williams, 2003). Increasing age associated with illiteracy is understood to be related to patients' reduced cognitive function, poorer education and increased poverty (Estrada, et al., 2000). Educational literature is not always culturally appropriate which increases barriers (Wilson, et al., 2003). Conventional educational material disadvantages people as it does not include all language, beliefs and values (Ibid).

Appropriate educational resources need to be developed. Currently the written educational information has discrepancies of the targeted reading level (Estrada, et al., 2000; Fang, et al., 2009; Wilson, et al., 2003). Estrada et al. (2000) accentuate that written material is efficient and inexpensive to produce. However, it is regularly written at a year nine or higher educational level which does not correlate to a person's actual reported reading ability, which is usually three to five years lower than the self-reported level. Estrada et al. (2000) describe the mean readability as year eleven which contradicts Wilson et al. (2003) who state it is year seven to eight. Wilson et al. (2003) maintain written material is only published in English, with no reference to health behaviours, illness, healing systems and practices, food preferences or dietary restrictions for minority groups. Fang et al.

(2009) highlight that patients with low literacy and little English are dependent on non-verbal communication for education which potentially increases the likelihood of misunderstanding.

Doctors and other disciplines commonly use the medical model to learn, where knowledge of disease and anatomy and physiology are priorities. Whereas patients learn via the health-belief model which addresses patients' concerns of symptoms and experience (Fang, et al., 2009). Wilson et al. (2003) suggest an interdisciplinary approach in the development of educational material using everyone's expertise, as well as including patients' feedback in the development of culturally appropriate material to improve outcomes, reduce barriers and health costs, and increase compliance. Increasing comprehension can be facilitated by producing brochures at lower literacy levels, and inclusion of large fonts and pictograms (Estrada, et al., 2000).

2.8.2 Education.

Educating patients transcends all areas of clinical practice and is essential in endeavouring to guarantee optimum outcomes for patients. Wyness (1990) and Mazor et al. (2007) embark in studying ways that could improve patients' education and therefore knowledge regarding Warfarin therapy. Structured educational programmes advance patient knowledge and satisfaction (Wyness, 1990). Mazor et al. (2007) concur that educational programmes are necessary on initiation, and add that ongoing refresher sessions are essential. Mazor et al. (2007) support the utilisation of narrative videos that use anecdotes. This teaching programme utilises a physician-patient stance. Wyness (1990) advocates nurses providing education programmes, however post-discharge nurses provided no further knowledge acquisition. Mazor et al. (2007) identifies increased patient knowledge post-video; although, non-adherence, unsafe beliefs and knowledge deficits were concerning. Wyness (1990) concurs, adding patients exhibited behaviours that were convenient, not safe practice, with increased complacency as time elapsed from education.

2.8.3 Structured Education, Self-Management and Clinic-Management.

The aim of increasing patient's quality of life within healthcare is paramount. Education increases Warfarin therapy self-management endorsed by improved INR,

adherence and convenience (Khan, Kamali, Kesteven, Avery, & Wynne, 2004) After one education session INR improved with self-management (Fitzmaurice et al., 2005; Gaddisseur et al., 2003; Khan, et al., 2004; Sawicki, 1999). Conversely, no significant difference was uncovered when comparing self-management to PHC clinic-management (Fitzmaurice, Murray, Gee, Allan, & Hobbs, 2002) or pharmacist-managed (Lalonde et al., 2008) for INR control.

People involved in Warfarin self-management are customarily younger and male (Fitzmaurice, et al., 2002; Fitzmaurice, et al., 2005). Gaddisseur et al. (2003) concur adding that this group is more active and have an increased interest in technology which perpetuates motivation. Conversely, Khan et al. (2004) see the impact of age as negligible, but report that older people find clinics to be more favourable for convenience. Conventional clinics are less expensive to operate (Fitzmaurice, et al., 2005). Self-management increases self-efficacy, autonomy, freedom to travel, reduced loss of work time, reduces risks and complications (Gardiner, Williams, Mackie, Machin, & Cohen, 2004; Khan, et al., 2004; Sawicki, 1999). Self-management is more convenient, safe and reliable to highly motivated patients (Fitzmaurice, et al., 2002; Fitzmaurice, et al., 2005; Gardiner, et al., 2004). Correspondingly, self-management requires frequent monitoring (Fitzmaurice, et al., 2002; Khan, et al., 2004; Sawicki, 1999) and increased outlay for appliances and sundries (Gardiner, et al., 2004; Khan, et al., 2004; Sawicki, 1999). Fitzmaurice et al. (2005) concluded that people with poor adherence exhibited improved INR control with self-management confirming that the benefits of self-management are extensive.

2.9 PRIMARY HEALTHCARE

Primary Healthcare providers have long-term relationships with patients. The next sections will discuss how PHC is positioned to manage Warfarin therapy. Relationship with health professionals and long-term medication usage are important for people who take Warfarin and this will be discussed. Following this, the practice nurses' role will be discussed, concluding with qualitative literature and two recently acquired studies which focus on patients' experiences of Warfarin.

2.9.1 How it works.

Primary Healthcare is the ongoing provision of healthcare within a community context, which encompasses acute to chronic management through the spectrum of ages (Pullon, 2007). Underpinning PHC is social justice, equality, self-management and a broad concept of health (Pullon, 2007). As well as PHC being the first point of healthcare contact for many, it provides comprehensive healthcare over time and co-ordinates care between the primary-secondary interface (Pullon, 2007). A team provides collaboration and shared ownership in healthcare by a partnership with the patient (Pullon, McKinlay, Stubbe, Todd, & Badenhorst, 2011; Toop, 1998).

The high quality of service delivery is an essential component of the therapeutic relationship. Important components within PHC include service delivery to practice populations, improvement of access, support of patients, utilisation and optimal communication (Pullon, 2007). Patients and health practitioners regard teamwork as an essential component within PHC that enhances quality. Trust, communication, and regular contact is viewed by patients as essential (Pullon, et al., 2011). Patients have reported Warfarin monitoring in PHC as preferentially providing safety, improved access and continuity of care (Rodgers, Sudlow, Dobson, Kenny, & Thomson, 1997).

Improved quality of life and health status is associated with effective PHC teamwork within the context of long-term condition management (Pullon, 2007). Caring for a diverse population is complex and burdensome, therefore effective collaborative teamwork reduces the burden (Carryer et al., 2007a; Pullon, et al., 2011; Toop, 1998). Patients do not clearly understand the delineation of the changing roles within PHC, which can perpetuate confusion. Nurses are seen more often, co-ordinate care, communicate concerns and manage changes to care. However, the doctor is often regarded as the leader and knowledgeable by patients. Nevertheless, patients wish to participate in their own healthcare (Pullon, et al., 2011) and value partnership and exhibit trust (Toop, 1998). Pullon et al.'s (2011) qualitative study addresses patients' and health professionals' perceptions of PHC. Carryer et al. (2007a) and Carryer et al. (2007b) discuss long-term condition management and the struggle PHC experiences to provide this. Prior literature has

entailed commentaries utilising past literature and opinion. In some instances Pullon et al. (2011) and Carryer et al. (2007a) are inclusive of nurses as fundamental components of the PHC team.

2.9.2 Relationships with Health Professionals.

The relationships patients have with their PHC provider are integral to the continued beneficial outcomes for their health. This relationship is multifaceted and the key components of trust, satisfaction, compliance and partnership are essential for both parties involvement in the therapeutic relationship.

2.9.2.1 Trust.

Trust between a patient and health professional is fundamental to an ongoing relationship in PHC. In some instances literature agrees trust is essential, although complex (Kerse et al., 2004; Kraetschmer, Sharpe, Urowitz, & Deber, 2004; Krupat, Bell, Kravitz, Thom, & Azari, 2001). Application of a patient-centred approach is found to increase trust (Krupat, et al., 2001). Trust is also regarded as influencing patients' continuity of care and satisfaction (Kerse, et al., 2004). Kraetschmer et al. (2004) highlight patient trust does not indicate passivity in decision-making, with caring, communication and expertise seen as imperative. Patients preferring autonomy are less trusting of health professionals. Conversely, increased trust is conducive to roles of passivity and shared-approach. Females, reduced educational levels and people over sixty-five years are increasingly likely to exhibit blind trust (Kraetschmer, et al., 2004).

2.9.2.2 Continuity of care.

Continuity of care did not increase medication adherence or improve preventative outcomes. Kerse et al. (2004), suggests a 'ceiling-effect' to continuity whereby patients become complacent with their providers which may have affected study results.

2.9.2.3 Partnership/Patient involvement.

The roles and expectations within a therapeutic relationship have changed historically, from paternalistic and authoritarian methods to inclusivity of the patient's perspective, thereby incorporating a shift in approach. The need for health

professionals to have exemplary communication skills to ensure understanding is recognised (Kerse, et al., 2004; Kraetschmer, et al., 2004). As knowledge increases, patients move from a passive role to a more shared-care role (Kraetschmer, et al., 2004), and congruence between patient and health professionals' beliefs are inherent in power sharing. Correspondingly, this relates to coherence with trust, satisfaction and endorsement if professionals practice in a patient-centred approach (Krupat, et al., 2001)

2.9.2.4 Concordance.

Patient concordance with medication is essential. Kerse et al. (2004) purport there is increased medication concordance if patients and health professionals agree on medication. Additionally, Krupat et al. (2001) regard patient beliefs as necessary to negotiate care, which correspondingly increases trust. If patient and health professional beliefs are in alignment, trust is enhanced. Older health professionals are regarded as more authoritarian in their approach, however this is rejected by Krupat et al. (2001).

2.10 LONG-TERM MEDICATION-TAKING

Medication beliefs and adherence have been extensively studied. How this correlates to chronic illness and the necessity to take long-term medication appears lacking within Warfarin literature. Parallels are able to be transferred within the context of other long-term medications. Webster et al. (2009) recently studied long-term medication-taking with Warfarin. Warfarin is seen as differing from other medication as it necessitates vast routine, and treats symptoms for a recognized disorder.

2.10.1 Ranking of importance.

Dependent on patients' beliefs, medications are ranked in order of importance. The taking of medications is analysed, then accepted or rejected (Stack, Elliott, Noyce, & Bundy, 2008). Patients' identify overprescribing of medication; they analyse their medication and are only occasionally non-compliant even if medication is deemed important. However, if there are significant consequences, medication is more likely to be taken (Stack, et al., 2008). Dowell and Hudson

(1997) disagree and explain that fatal consequences do not deter transplant patients from intermittent medication usage.

2.10.2 Exert control.

The experimentation of medication timing, use and cessation was regarded as an ability of patients to have self-control and not a direct correlation on the quality of their therapeutic relationship with health professionals (Dowell & Hudson, 1997). Decision-making enables autonomy while, dichotomously it also represents a sign of an illness, failure or weakness, as well as a change in self-image (Dowell & Hudson, 1997; Pound et al., 2005).

2.10.3 Lay pharmacology.

Medications are an inherent part of our society. Although prescribed medication responsibility is mostly under the auspices of the doctor, who holds the power; patients hold the power of whether to take the medication (Pound, et al., 2005). Prescribing medication should be individualised and the need for making sense of the medications by understanding and knowledge is key to this concept (Pound, et al., 2005; Webster, et al., 2009). The perception that if medication is less powerful, it is therefore safer is a recurrent theme that is woven throughout several studies; a lesser dose denotes a safer drug (Dowell & Hudson, 1997; Pound, et al., 2005; Webster, et al., 2009). Patients distrust medications and apply caution when taking them which influences their acceptance (Dowell & Hudson, 1997; Pound, et al., 2005).

2.10.4 Concern.

The taking of long-term medication, the safety, side-effects and adverse drug reactions are all concerns patients have in regard to medications. The relationships patients have with health professionals are inherent in allaying concerns. Faith in health professionals and information regarding medication is seen to increase adherence (Dowell & Hudson, 1997; Pound, et al., 2005; Webster, et al., 2009). Certain classes of medications and concurrent chronic illness can increase patient concerns. In some instances literature reveals that patients experience stigmatisation, anxiety, discrimination, avoidance of social engagement, and fears on the effect of employment related to long-term medications for a chronic illness (Pound, et al.,

2005; Shiu, Kwan, & Wong, 2003). Pound et al. (2005) incorporate patients fear marginalisation regarding their medications. Marginalisation can affect beneficial treatment decisions, which directly correlate to deterioration of health as patients conform to societal pressures and rejection of medication (Shiu, et al., 2003). Patients' adherence is increased if they know the medication is safe. Pound et al. (2005) raise concerns this did not evolve in the literature they reviewed, even though previous studies acknowledge this aspect. Disregarding this prudent point led to unnecessary replication of studies. Pound et al. (2005) synthesis of literature provides collective analysis introducing evidence supporting adherence.

Patients do actively resist taking their medication, and this is perceived as a dimension that health professionals need to understand (Pound, et al., 2005; Webster, et al., 2009). Health professionals need to ask about and analyse patients' perceptions of medication and illness to understand their perspective. Denying illness can be interrelated to patients reducing medication, thereby reducing emphasis on the illness (Dowell & Hudson, 1997). However, adjustments were made with the length of time on medication, familiarity and increased knowledge (Dowell & Hudson, 1997; Webster, et al., 2009). The relationship to co-morbidities and poly-pharmacy can see accumulation of medication side-effects, thereby complicating regimens (Webster, et al., 2009). A solution espoused by Pound et al. (2005) is to develop safer medications at the level of licensing. Through longer probationary periods for new medications before released clinically; whereby safety and risk profiles can be comprehensively assessed. Pound et al. (2005) suggest reducing pharmaceutical dominance on the introduction of medications by transferring the authority back to clinicians. Clinician authority will enable delays in the introduction of new medication that have no long-term unbiased, independent robust analyses.

Patient-centred consultations inclusive of partnership improve long-term outcomes (Dowell & Hudson, 1997). Increased knowledge, power sharing and individualisation of the consultation increase the ability of patients and health professionals to engage. Enhancing medication concordance may be increased through patient decision-making, knowledge, understanding, satisfaction, safe medication usage and perceived quality of life (Dowell & Hudson, 1997; Pound, et al., 2005).

2.11 ROLE OF THE PRACTICE NURSE

Practice nurses' role within the management of Warfarin is sparsely documented in the literature. However, there is the ability to compare nurses' role and long-term condition management (LTC) of other conditions, with nurses' role in Warfarin management.

Warfarin monitoring involves several models of care, which range from secondary services to PHC, pharmacist led clinics to point-of-care testing (Lowthian et al., 2009). The differences in delivery service is seen as a weakness to safety and potential for errors (Lowthian, et al., 2009; Lowthian, Joyce, Duig, & Dooley, 2011). Although Warfarin monitoring is time-consuming and equates to an increased workload, PHC plays a pivotal role with ongoing management of this, with practice nurses at the forefront (Geevasinga, et al., 2004; Lowthian, et al., 2009; Lowthian, et al., 2011; K. Wright, 2010). Within the community it is important that health professionals work in a holistic manner. Practice nurses have an important role within ongoing communication and education with patients (Geevasinga, et al., 2004).

A NZ study found that nurses within PHC, although monitored patients in differing in ways, offered continuity, holism and a comprehensive knowledge of patients. Nurses spend increasingly more time supervising Warfarin monitoring than doctors (Geevasinga, et al., 2004). However, in Australia the practice nurse role is still developing and continues 'task-orientation' in nursing work. There is an acknowledgement of the increased autonomous role that exists in other similar countries. Here lies an important opportunity in regard to monitoring, educating and communicating of Warfarin therapy for nurses (Lowthian, et al., 2011) which assists doctors and encourages collaboration (Lowthian, et al., 2009). Wright (2010), a PHC doctor devolved responsibility of monitoring Warfarin to a nurse-led system utilising standardised protocols based from the British Colombian guidelines. This was initiated after auditing previous ad-hoc monitoring against standardised protocols. Ad-hoc monitoring was doctor-time intensive, while standardised protocols were effective, increased efficiency and improved patient outcomes.

Implementation was doctor-initiated, with the nurses' perspective and experiences not discussed (Wright, 2010).

The role of the practice nurse is changing and opportunities, although daunting to some, are challenging to the nursing profession. The devolution of responsibilities previously undertaken by doctors to nurses and increased autonomy in clinical practice requires up-skilling and increased knowledge. Nurses have needed to increase their practical skills, assessment and diagnostic skills in addition to their previous roles (Sheridan, Finlayson, & Jones, 2009) To keep abreast of this situation sees the challenge of clinical practice and incorporation of increased educational requirements (Richardson & Gage, 2010), however this diversity directly influences the quality of patient care. Practice nurses have seen their roles change with the devolution of health services to the community (Sheridan, et al., 2009). Practice nurses are situated to reduce health inequalities, increase access, work collaboratively in partnership and provide opportunities for patients (Sheridan, et al., 2009). Working within the business model is challenging to nurses who work alongside doctors, who own the 'business', but are also colleagues (Richardson & Gage, 2010).

Patients are often unaware of the role of the practice nurse and the skills and knowledge they bring to the practice team. The ability for nurses to develop their role will address their invisibility and anonymity from a patient's position. At the same time valuing the relationships practice nurses have which assists in reducing barriers (Kenealy, Docherty, Sheridan, & Gao, 2010). Kenealy et al.'s (2010) study provocatively suggests practice nurses should see all patients before doctors, which will enhance patient outcomes.

Recognition of advanced educative needs is identified to support practice nurses' advancing roles towards independence and autonomy (Ashworth & Thompson, 2011; Kenealy, et al., 2010; Richardson & Gage, 2010). Long-term condition management acknowledges the important role practice nurse have, which can be congruent with Warfarin therapy (Ashworth & Thompson, 2011). Management of LTC involves teamwork and supports utilisation of nurse-led clinics. Kenealy et al. (2010) argues nurses seeing patients for planned and opportunistic

presentations thereby supports nurses' role development. Consultations assisted by information sharing and communication build therapeutic relationships, with clinical leadership increasing co-operation and commitment by nurses (Ashworth & Thompson, 2011).

2.12 QUALITATIVE LITERATURE

While some studies on Warfarin use have been undertaken from a qualitative approach, these are through the lens of health professionals or carers. Both qualitative studies retrieved are from the same authors, utilising focus groups in hospital clinics. The authors' postulate concerns from health professionals, patients and carers regarding inadequate knowledge and understanding of Warfarin. Patient education was regarded as ineffectual, with insufficient resources acknowledged by participants (Bajorek, Krass, Ogle, Duguid, & Shenfield, 2006; Bajorek, et al., 2007). Bajorek et al. (2007) report health professionals assumed other colleagues were responsible for education, leading to patients feeling abandoned. Nursing perspectives surprised Bajorek et al. (2006) with their lack of involvement and knowledge regarding monitoring, management and medication interactions. Nurses regarded doctors as managing Warfarin and perceived there was no role for nurses. Bajorek et al. (2006) consider role development for nurses as important, but had been overlooked. The need for education to increase nursing knowledge is paramount which is congruent with Richardson and Gage's (2010) NZ-based study.

2.12.1 Patient Experience.

Initially no qualitative studies pertaining specifically to patients' experience were retrieved. On review of the literature after completion of interviews, two were located, not having been found in previous searches. Both studies involved elderly patients with atrial fibrillation. One, undertaken in Australia, involved a teaching hospital, the other, from a large Canadian family practice which was attached to a teaching hospital. The literature agrees that doctors make the decisions at initiation of Warfarin. Patients experienced increased trust in health professionals if they provided individualised and continuity of care (Bajorek, Ogle, Duguid, Shenfield, & Krass, 2009; Dantas, et al., 2004). Patients felt education was minimal and insufficient. Bajorek et al. (2009) extrapolated that education was occasionally

replaced by myths obtained from others. Conversely, participants who were 'Warfarin-naive,' with no prior exposure possessed reduced fear. Dantas et al. (2004) maintain satisfaction with health professionals directly correlated to patient adherence.

2.13 CONCLUSION

Chapter two has reviewed literature in regard to the statistics for CVD internationally and nationally. The implications for taking Warfarin related to this have been considered. Warfarin the medication was discussed and it has a narrow therapeutic window; that is a close proximity from being sub-therapeutic to toxic with adverse consequences. Warfarin requires close monitoring by way of a laboratory test for INR which encroaches into patients' lives. Warfarin interacts with diet and medication making it a complex medication to adhere to. The myths associated with this drug are well recognised.

The effect of literacy and patient education about Warfarin result in the patient's ability to understand and gain knowledge with this medication and is lacking effective resources and programmes. The ongoing self-management and monitoring by differing clinics or people were discussed with a range of health professionals and ways of testing discussed.

Within the PHC context there are relationships that encourage ongoing continuity of care, increased access of which trust and satisfaction are integral for open and honest communication, with cognisance of medication-taking beliefs. Although patients do not always take medications as prescribed, there are similarities with long-term conditions that require ongoing medication adherence. Patient autonomy, control and knowledge are influential in this concept.

Nurses' contribution to Warfarin monitoring is different from practice to practice. Education is seen as essential in the development of this role. There is immense potential for practice nurses to develop this role with LTC. In NZ, nurses spend more time than doctors monitoring Warfarin. Patients regard nurses' work as invisible, they are unaware of the skills and knowledge nurses have. Practice nurses

are situated to reduce health inequalities, increase access and work collaboratively with colleagues and patients.

There is a paucity of qualitative literature on Warfarin, with the main studies retrieved from the same authors utilising health professionals' perspectives. The two studies retrieved on last review of the literature were undertaken in hospitals and utilising only patients with atrial fibrillation, some of who had care-givers answering for them. It is this lack of qualitative studies that influenced the need to develop my research. The next chapter will discuss the qualitative inductive methodology utilised for this study.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

Chapter three discusses the methodology that underpins this research. The qualitative approach that encompasses this research will be considered. A general inductive methodological approach utilising Thomas' (2003) framework for this research will be discussed. The researcher's rationale for utilising an inductive approach will be explained. The researcher's decision trail addressing the context of participants, recruitment, and interviewing, ethics and inductive data analysis will be discussed to demonstrate the enhancement of rigour, trustworthiness, confidentiality and validity of this research.

3.2 QUANTITATIVE/QUALITATIVE RESEARCH

There is value in both quantitative and qualitative research methodologies within nursing, with each research approach having strengths, deficiencies and limitations. However, it is important to utilise the correct methodology to depict research as accurate for the phenomenon to be investigated (Polit & Beck, 2008). The choice of method relates to the research question and its appropriateness for the research problem (Polit & Beck, 2008). Both quantitative and qualitative research approaches are fitting for nursing research (Gerrish & Lacey, 2007).

Quantitative and qualitative research has different characteristics that originate from different scientific traditions (Gerrish & Lacey, 2007). Quantitative research methods have structured standardised specific designs which are used to test hypothesis and statements (Polit & Beck, 2008). Quantitative research highlights the mechanistic, objective and hypothesis-driven methods. Deficiencies of scientific methods include the lack of explanation of any relation to humanness. Underpinning

quantitative methodology is the empiricism or positivistic traditions of scientific truth and laws that are emergent from observed and measured study. Positivistic tradition is said to reduce bias within these research methods and therefore increase confidence in findings (Gerrish & Lacey, 2007).

Qualitative research is interpretative and emphasises meaning and understanding through human action and behaviours, and originates from the social sciences (Gerrish & Lacey, 2007). The difficulty encountered in explaining the human experience by objective means and the ability to look at a person in context in a natural setting has seen qualitative research design expand (LoBiondo-Wood & Haber, 1998). Qualitative research designs aim to develop rich understanding as it exists in the real world, by individuals, in context (Polit & Beck, 2008). Qualitative research enables an approach that is contextual and consequently research can explore all dimensions of human uniqueness (LoBiondo-Wood & Haber, 1998; Polit & Beck, 2006). Qualitative research is ably placed to describe the participant's perspective as it is embedded in a naturalistic stance where there are multiple realities that are subjective (Driessnack, Sousa, & Mendes, 2007). An inductive approach allows the research to be flexible and adjustable. An emergent design develops as an individual's story unfolds, hence viewpoints are uncovered which are not evident at the outset (Polit & Beck, 2006). An inductive approach highlights interpretation and meaning by human dialogue, as well as recognition of the prior understanding of the researcher (Polit & Beck, 2006). The difficulties encountered in researching the human experience are addressed within this approach.

3.3 INDUCTIVE METHODOLOGICAL APPROACH

An inductive approach extracts conclusions, and describes, explains and generates theory (Gerrish & Lacey, 2007). Inductive approaches originate with the purpose of discovery and explanation of a phenomenon when little is known. By focusing on human experience and meaning, the inductive approach uncovers complex human behaviour and enlightens a broader understanding and deeper insight (LoBiondo-Wood & Haber, 1998).

The general inductive methodological approach that underpins this research is based on the framework of Thomas (2003). An inductive approach utilises a less complicated methodology than traditional qualitative methodologies by an efficient method of qualitative data analysis (Thomas, 2003). The generalised inductive approach evolved from health and social sciences as a means to analyse data guided by straightforward, comprehensible, orderly procedures and steps (Thomas, 2006). The qualitative inductive approach encourages the identification of key themes from naturalistic data, which supports emergent research findings without the confinement imposed by structured and controlling methodologies (Thomas, 2003). The ability to incorporate inductive analysis is consistent with an emergent design where themes are not constrained (Thomas, 2006).

The employment of an inductive approach enables research findings to emerge from data, progressing to the evolution of themes. An inductive approach illuminates themes rather than obscuring them (Thomas, 2003). The innovation of an inductive approach explicates procedures to allow data to be condensed into a manageable format. There is an ability to show a clear link from the research aims to the findings, highlighting transparency and justifying the study aims (Thomas, 2006). Data is able to portray experience, encompassing the development of theory (Thomas, 2006). These strengths and steps improve the researcher's ability to interpret and understand data.

3.4 WHY AN INDUCTIVE APPROACH?

The purpose of this research originates from a deficit of qualitative research from the patient's perspective. An inductive approach will enable the researcher to develop a robust understanding of the patient's experience of Warfarin therapy within a PHC context. It enables the research to explore the patients' experience of initiation, monitoring, education and management of long-term Warfarin therapy. To explore the issues, lifestyle, actions, and beliefs of patients as well as the patients' understanding of their relationship with PHC professionals, including dynamics, rapport, and decision making processes regarding Warfarin therapy.

There is an ability to show a clear link from the research aims to the findings, highlighting transparency and justifying the study aims (Thomas, 2006). Data is able to portray experience, encompassing the development of theory (Thomas, 2006). These strengths and steps improve the researcher's ability to interpret and understand data. The suitable or effective methodology encompasses the researcher's awareness of the necessity to highlight each participant's personal experience. An inductive approach enables a deeper understanding, interpretation and description of Warfarin therapy. There is a plethora of quantitative literature that portrays research from a health professionals' perspective in relation to Warfarin therapy as discussed in Chapter 2, the Literature Review.

The deficit of qualitative literature in PHC in NZ, therefore led the author to consider a qualitative inductive approach which is ably positioned to describe the participant's perspective. The inductive approach involves explanation of the depth of richness in the data, which is context bound and embraces the wholeness of a person while exploring all dimensions of the human uniqueness (LoBiondo-Wood & Haber, 1998).

3.4.1 Nursing Research Historically.

Historically, nursing has struggled to find research methodologies that positioned themselves to encompass all aspects of importance to nursing. The mechanistic, positivist and objective quantifiable scientific methods, are constraining for nursing (Gray & Platt, 1991). Nursing historically has been embedded within social constructs of stereotypical gender and medical dominance, which is sustained by the influence of the media (Gray & Platt, 1991). Nursing has evolved through discourse on the art and science of nursing. The inclusivity of degree level and doctorate pedagogy and the development of nursing theorists have endorsed the ontology and epistemology of nursing as its own unique discipline. The holistic nature of nursing has been suppressed with the experimental, objectifying and quantification of traditional scientific research methodologies (Omery, 1983).

Nursing practice is situated, embedded, contextual, temporal, historical and cultural. Nursing requires the incorporation of the elements of caring, humanism and holism within research methodologies (Gray & Platt, 1991). Nursing research has

developed a more humanistic disciplinary approach by the increased utilisation of qualitative methodologies. The science of psychology pioneered this research shift, which developed from a failure of quantitative methodologies to effectively explain human beings. There is a necessity to have methodologies that recognise people's experiences and correspondingly; to endorse an ability to study human beings in a natural setting and value all data (Omery, 1983).

Benner, a nursing leader and theorist acknowledges nursing research positions itself within a contextual, embodied and situated perspective, which has the ability to show meaning in everyday practices. Benner (1984) cautions the importance of not de-contextualising or trivialising ordinary meaning.

3.4.2 Warfarin Therapy.

An inductive approach appropriately enables participants who experience Warfarin therapy to participate. The researcher conducts the interviews while recognising and setting aside their own bias (LoBiondo-Wood & Haber, 1998). Data analysis occurs through a process of breaking down data, coding, then reordering and reconstituting (Gerrish & Lacey, 2007). Carr (1994) perceives problems with reliability and rigour with qualitative research, as the researcher is connected to the research, which threatens validity because maintaining detachment is unattainable. Validity, also known as credibility in qualitative research, is addressed by reflexivity. The researcher can critically reflect on the research process and analyse the influence they have on data collection. A well prepared experienced researcher increases a study's credibility (Patton, 2002). Reflexivity recognises the researcher is fundamentally entwined with the research and may influence or introduce bias to the research (Gerrish & Lacey, 2007).

3.5 PARTICIPANTS

The underlying aim of this research is to ensure that the experience of a range of patients in PHC involved on long-term Warfarin therapy is portrayed. For this purpose there needed to be a specific selection criteria in the sampling frame, to ensure a richness of information. A sampling frame lists facets of the population from which the sample is extracted (Polit & Beck, 2008). The sampling was

purposive where participant selection is seen as purposeful and intentionally chosen in direct accordance with the aims of the study (Coyne, 1997; Patton, 2002), with the explicit purpose of obtaining diverse representation. Purposive sampling enables a focused enquiry and allows the researcher to learn more about unusual cases, eliminating the need to meet pre-determined criteria (Patton, 2002; Polit & Beck, 2006). Although rigour is questioned in qualitative studies, the use of a sampling frame that maps out the sampling decisions is one way to determine rigour in qualitative research (Gerrish & Lacey, 2007).

The sample involved patients from urban health facilities who were invited into the study. Involvement was voluntary, informed consent was obtained and withdrawal from the study was feasible at any stage. There was an attempt to include an even distribution of males and females, diversity in age, differing social-economic factors and ethnic diversity. Participants were not excluded from the study because of their medical indications for Warfarin therapy. The sample would not exceed ten. Ten was chosen because it was pragmatically achievable within the time constraints of this thesis and the large amount of data that was anticipated to be collected.

3.6 RECRUITMENT

Recruitment information was sent to urban health facilities through pre-existing weekly information bulletins and followed up by telephone. Health facilities were also sent a query builder (see Appendix A). A query builder is a utility within Medtech 32 software that enables practices to extract information from their patient populations utilising specific criteria (Medtech Global Ltd, 2011). Identified patients were filtered and initially approached by their PHC team, to ascertain interest in participating in the study. Advertisements were displayed in health facility waiting rooms. The researcher's own networks were utilised to identify interested practitioners and to ensure diversity of participants, as selective recruitment from different geographical areas assisted in diversity of participants. The recruitment process is outlined by the flow chart in Appendix B. The information sheet (Appendix C), flyer (Appendix D) and consent form (Appendix E) were all part of the ethics committee application process and the information sheet and consent form

are version two. The query builder (Appendix A) was developed by the researcher to encompass the inclusion and exclusion criteria.

Inclusion criteria were:

- Taking Warfarin prescribed by GP.
- Live within the urban area and are enrolled patients.
- Have been taking Warfarin for longer than 3 months.

Exclusion criteria were:

- Under 18 years old.
- Monitored by the haemostasis clinic at the Public Hospital (not PHC).
- Taking Warfarin temporarily.

3.7 QUALITATIVE INDUCTIVE INTERVIEWS

The purpose of this research is to elicit a rich description of the experience of participants in regard to Warfarin therapy. To achieve this, data was obtained by semi-structured interviewing. Interviewing allows participants to describe their point of view, enabling the researcher to probe for detail, and clarify pertinent points (Starks & Brown-Trinidad, 2007) at the time of data collection.

Interviews commenced with general questions and then became more focused. An interview guide was utilised to ensure the interview stayed focused (Appendix F). The interview guide was to ensure the researcher could build rapport and listen intently, as opposed to being distracted (Polit & Beck, 2006).

The use of interviews as a data collection technique was to increase the response rate of participants by a more personalised way of collecting information. Purposive sampling included a variety of people, especially marginalised people in the sample who may otherwise be excluded. Interviews ensured there was no misinterpretation as clarification could occur instantaneously, and increase information through observation (Polit & Beck, 2006). Allowance of sufficient time at interviews increased the credibility and reliability of the study by increasing trust

and rapport with participants. Through this a deeper understanding of their experience was encapsulated (Polit & Beck, 2006).

The researcher recognises a nurse's knowledge base is influential and could potentially affect the research process. However, there is also an ability to be impartial and non-judgemental and listen to participants' experiences. Reflection is viewed as an important component, which was undertaken by the researcher when writing field notes. The utilisation of supervisors to discuss any issues that arose during interview assisted with reflection and ensured reliability.

Interviews took place in participants' own homes or at a designated urban health facility. Participants were given a choice as to where and when the interview took place. Interviews ranged from thirty-five to eighty minutes duration. All interviews were audio-taped with the permission of participants. Participants had the right to stop the interview at any stage. Interviews were transcribed by the researcher and returned to participants for validation. Participants could delete any part of transcript if they no longer wanted to disclose information, or add any comments if they wanted. Four participants declined to have their transcripts returned for validation. Of the six transcripts returned for validation, no alterations were made by any participant.

3.8 ETHICS

Ethical considerations encompass all aspects of the research process; therefore it is imperative that ethics is addressed in every aspect of this research (Robley, 1995). The ethical issue of importance is the consideration of participants, and their protection. Ethics involves obtaining consent, and maintaining confidentiality, privacy and anonymity (Gerrish & Lacey, 2007). Qualitative research is more problematic in regard to ethics as complete information cannot be given relating to the unstructured nature of data collection and the unpredictability of the time and number of people to interview (Ford & Reutter, 1990). This follows the emergent design of qualitative studies; therefore informed consent needs to be continuous.

3.8.1 Risk of harm.

The risk versus benefit of conducting this research needs to be analysed to ensure the ethical principles of beneficence and non-maleficance are adhered to (Polit & Beck, 2006). This ensures the risk to participants is negligible, while recognising that the benefits may be intangible and unidentifiable (Robley, 1995). Although stringent perseverance to reducing risk and maximising benefit was attempted, there may have been unforeseen circumstance where discussion during data collection could have led to distress. Research would have been discontinued at this point.

3.8.2 Informed consent.

It is essential that participants understand informed consent. Consent involved providing adequate information (Appendix C) when invited to participate. Comprehension of the information provided ensured there was freedom of choice. The familiarity of the right to voluntary consent (Polit & Beck, 2006) was discussed as well as the right to decline or withdraw at any stage (Gerrish & Lacey, 2007). As a prerequisite, the consent form was clear and unambiguous (Appendix E).

3.8.3 Confidentiality.

Confidentiality incorporates privacy and anonymity. Anonymity can be problematic in qualitative studies due to the small sample size (Polit & Beck, 2006). Confidentiality was upheld by elaborate procedures and utilising fictitious names (pseudonyms) (Polit & Beck, 2006). The privacy of participants was increased by secure data storage. Written transcripts are kept in a locked cabinet; electronic transcripts and data analysis were backed up, locked away, and computers were security coded (Gerrish & Lacey, 2007).

3.8.4 Ethics approval.

Upholding of ethical principles is the responsibility of all researchers. Initially approval from the University of Otago Health Sciences, Board of Studies and the Upper South A Regional Ethics Committee was obtained. Consultation with Māori was obtained through Elizabeth Cunningham, Research Manager–Māori; University of Otago, to ensure that Māori were included and represented appropriately throughout this research. Discussion with Wendy Dallas-Katoa, former

Māori advisor for PHO prior to interviewing Māori participants was sought. The researcher was prepared and acted in a correct manner according to the Māori culture which was respectful of their perspective. Preparation involved personal discussion on comportment before, during and after interviews. Prior to commencing interviews explanation of correct introduction and greeting involving a 'mihi' and 'pōwhiri' was explained to the researcher.

The pre-requisite of two supervisors from the University of Otago also substantiates the upholding of ethical principles. The role of the researcher when utilising participants from clinical practice can also involve role confusion and power differential which could potentially be problematic (Gerrish & Lacey, 2007). As a researcher it was imperative that participants were not open to coercion and were treated with respect, dignity and autonomy. Participants were therefore not sought from the researcher's own clinical practice. Participants were given two weeks to read the information sheet before any contact with the researcher to participate was sought. Participants could withdraw at any stage. Two participants consented to interviews, however they withdrew before interviews commenced; one for personal reasons and one changed his mind and could not see the value of the research.

3.9 INDUCTIVE DATA ANALYSIS

Data analysis is one of the most crucial and intellectually demanding parts of the research process, and needs to be transparent, rigorous and systematic, to increase trustworthiness (Gerrish & Lacey, 2007). A generalised inductive approach is straightforward, convenient and efficient way of analysing data that emanates clear links between data and research aims (Thomas, 2003).

Inductive data analysis is guided by the evaluation objectives (aims) of the research. Analysis commences through multiple reading and interpretation of the data as a whole. The findings are influenced by the research aims, in conjunction with data analysis. The research aims enables an increased intensity of focus for the researcher when analysing data (Thomas, 2006).

Several steps are adhered to in inductive analysis. Naturalistic data is uniformly formatted to assist the researcher in interpretation, and development of categories and themes (Thomas, 2006). All transcripts are read in detail to ensure the researcher is familiar with the content, to gain an understanding, and enhance the ability for theme development. Continuous reading identifies categories and themes (Thomas, 2003).

Categories are divided into upper and lower level. Upper levels are general categories that are derived from the aims as listed on page seven. Lower levels are specific categories derived from numerous reading and are called 'in vivo' coding (Thomas, 2006). Continual revision of categories enables major theme development. Categories are developed from data and contain key themes. Initially a word selected or short phrase is developed which has inherent meaning to the data. Following on is a category description. The description portrays the meaning and key characteristics of the category (Thomas, 2003).

Inductive coding creates actual phrases or meanings of specific data segments (Thomas, 2003). It is acknowledged that there is an abundance of data extracted from interview and segments of data can have multiple meaning and interpretations. Conversely, considerable parts of data may not be attributed to any category, and may not be relevant (Thomas, 2006). Inductive data analysis is indicative of a naturalistic emergent design that qualitative research represents.

Continuing refinement and revision of each category and theme see the researcher searching for sub-topics, contradictions or insights. Appropriate quotations support findings and explanations of categories and themes. Themes are continually revised until they are reduced with the intention to develop between three to eight themes. Theme development reports core messages from participants (Thomas, 2006).

The researcher transcribed all interviews to allow data immersion and the connection between the whole and segments of the data. The text was returned to participants for clarification and validation which increases validity. Data extraction is acknowledged as laborious, labour intensive and requires the researcher to

immerse themselves in the data. Although computer software can enable data to be manipulated in a way which is not able to be manually undertaken, the researcher deemed this was not appropriate for this research. All data analysis was manually extracted so rigorous analysis by the researcher generated decisions, interpretation and understanding, enabling category and theme development. Data immersion permitted a deeper awareness for the data and interrelationships.

In this thesis the process proceeded as follows. Reading and re-reading of the transcripts enabled movement between all and individual transcripts, as well as sections of transcripts, enabling category and theme development by the researcher. The development of categories emerged from the movement between parts and whole of transcripts. Key words were initially selected which developed into categories. Categories were guided by the repeated reading of transcripts in conjunction with the aims of the research. Theme development evolved from categories. Themes were continually revised and quotations supported development. Six key themes emerged and are listed in Chapter 4: Analysis and Findings; Table 3; ‘Summary of categories, sub-themes and themes’ on page sixty one. Table 1 below is an example of how category, sub-theme and theme development transpired.

Table 1: Example of category/subtheme/theme development.

Raw data.	Category.	Sub-theme.	Theme.
“I took it with a grain of salt.” “Live your life as much as you can.”	Normalcy.		IMPACT.
“I could’ve had a stroke.” “You stand the risk of it clotting around the valve.”	Consequences		
“Oh No I forgot my	Adherence.		

<p>Warfarin.”</p> <p>“I had no idea whether I’d taken them or not.”</p> <p>“..he [doctor] tested my blood levels and it was nineteen. Amazing.”</p> <p>“...it was 18 hours of bleeding. They couldn’t stop it, they couldn’t control it.”</p>	<p>Hospitalisations.</p>	<p>Quality of life.</p>	
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3.10 TRUSTWORTHINESS

The generalised inductive approach provides procedures for data analysis. However, the professional integrity of the researcher, to be faithful to the data, to ensure good judgement and insight into coding still needs upholding (Polit & Beck, 2006). Thomas (2006) recognises that different researchers may produce differing interpretations.

Increasing quality and therefore trustworthiness in qualitative research led to the development of a framework by Lincoln and Guba (1985). They concur credibility, dependability, transferability and confirmability are ways to accomplish and increase confidence, expertise and integrity in qualitative research (Gerrish & Lacey, 2007; Polit & Beck, 2006, 2008; Thomas, 2003, 2006). Credibility is improved by debriefing, and dependability increased by performing a research audit comparing data and interpretation with others (Thomas, 2003, 2006). Debriefing involved reflecting on each part of the research process. Debriefing was undertaken independently by the researcher to ensure stringent dedication to exemplary principles in the conduct of this research. The researcher also had regular meetings and discussions with supervisors to ensure conduct through the research process was exemplary. All participants were aware the researcher was a nurse. Credibility was potentially increased by the trust participants’ exhibited and the openness of their responses at interview. Two participants confirmed the researcher was a nurse then

proceeded to give intimate details previously not disclosed to other health professionals. Knowledge that the researcher was a nurse may potentially alter the depth of discussion by presuming prior knowledge and therefore not verbalising pertinent issues during the interview. Within a GP practice setting there could be an assumption by participants that all GP practices are linked thereby influencing the responses given. The utilisation of the researcher's own practice population was therefore excluded.

Trustworthiness is optimised through 'consistency checks', where coding is undertaken independently by researchers. 'Member checks' increase credibility and are attained through summarising main points during and at the end of interviews with participants, for clarification. Transcripts can be returned to participants for validation to augment credibility (Thomas, 2003, 2006), as explained on pages fifty-one and fifty-four.

To improve the rigour and trustworthiness of the study, recognition of my own biases and presuppositions were noted, to ensure my credibility was unquestioned and that there was confidence in the research interpretation and findings. Summarising the main points at interview enabled immediate clarification of meaning, increasing credibility and dependability. The first two transcripts of interviews were also independently analysed by my two supervisors. Discussion with supervisors regarding categories and themes increased the credibility, dependability and confirmability by interpreting in unison. Generalisability may be possible within an inductive study, but has a differing approach from quantitative methodologies. The ability to see common themes within individual's experiences leads to the supposition that the data is applicable to a wider population group (Polit & Beck, 2006; 2008).

3.11 CONCLUSION

The methodology of this research has been discussed with the reasons for choosing a qualitative methodology. An inductive approach incorporates a human, situated and contextual research methodology. The rationale for the decision process

for this research has been discussed as well as the historical context of nursing research, to embrace an inductive approach.

An inductive approach by Thomas' (2003) framework enables a robust understanding of participants' experience and is placed to systematically guide analysis of data. An inductive approach has seen clarification of the modus operandi to include participants, recruitment, interviewing, ethical considerations and data analysis in the context of this methodology. Trustworthiness was augmented through strategies to increase credibility and dependability through consistency and member checks, as well as independent coding, analysis and interpretation. The next chapter will discuss the analysis and findings.

CHAPTER 4

ANALYSIS AND FINDINGS

4.1 INTRODUCTION

Chapter four presents the findings of the inductive data analysis outlined in Chapter three, the Methodology Chapter. The size of General Practices utilised are presented in Table 2. Participant profiles are presented in Table 3. The process of data analysis, interpretation and understanding found commonality of meaning, which enabled theme development. Inductive analysis required continual revision and refinement of raw data, until findings reflected the fundamental experience of participants.

Purposive sampling was utilised to select people for this study to elucidate an in-depth understanding of patients' experience of Warfarin therapy (Patton, 2002). Sampling endeavoured to recruit people from a diverse age range, from differing geographical areas within the city boundary, as well as people from differing socio-economic backgrounds, cultures and indications for Warfarin therapy. Fieldwork commenced on 19th November, 2010 and concluded on 20th January, 2011. The specific numbers of participants contacted are unknown as responsibility to make initial contact was delegated to individual practices to reduce coercion. Twelve people were contacted in total by the researcher. One declined after deliberating and another withdrew due to family commitments. Ten healthcare facilities agreed to participate. Five healthcare facilities were utilised as the sample size had already been achieved prior to the remaining healthcare facilities contacting the researcher.

Table 2: Type of General practice participants recruited from.

Small practice.	Medium practice.	Number of General Practitioners.	Number of practice Nurses.
2		2	1 - 2
	3	4 - 5	4 - 8

KEY:

Small Practice: 1 – 3 (GP)

Medium Practice: 4 – 7 (GP)

Large Practice: 8+ (GP)

The findings culminate in six key themes extrapolated from the data. The categories, sub-themes and themes are demonstrated by Table 4 (page 62). The themes are presented in an open network (Thomas, 2006), with no hierarchal order of significance. Each theme has excerpts from transcripts as illustrations to support findings. Themes are interrelated and some themes overlap. To assist in explanation and the subtle differences between themes the researcher has separated the themes of knowledge acquisition, information/misinformation and education into separate themes. Knowledge acquisition pertains to the understanding of knowledge by participants and is effected by an individual’s cognitive ability, their motivation, as well as experiential learning.

Information/misinformation is the gathering of information from differing sources by participants. Some information was specifically sought; other information was forced onto participants without request. Information included the internet, but also the influence of frivolous statements or beliefs espoused by family and other people. Not all information was correct or credible. Education specifically examined the formal process of receiving initial education and the lack of preparedness participants verbalised. The findings reflect the aims of this study as stated on page six, as well as allowing the research findings to emerge without restraint reflecting participant’s experience.

Table 3: Participant profile.

Name	Gender	Age Band	Ethnicity	Time on Warfarin	Diagnosis	Employment data
Ann	Female	65–69	NZ European	3 years	Atrial-Fibrillation	Retired.
Nick	Male	40–44	NZ European	28 years	Aortic Valve Replacement.	Professional.
Miriama	Female	65-69	NZ Māori	7 years	Atrial Fibrillation	Beneficiary.
Cheryl	Female	55-59	NZ European	4 years	Atrial Fibrillation	Manual Employment
Elizabeth	Female	85-89	NZ European	5 years	Atrial Fibrillation	Retired.
Richard	Male	65-69	NZ European	1 year.	Aortic Valve Replacement	Retired
Linda	Female	50-54	NZ Māori	6 months	Aortic Valve Replacement	Beneficiary.
Steve	Male	60-64	NZ European	1 year	Aortic Valve Replacement.	Manual employment.
Alan	Male	70-75	NZ European	15 years	Mitral regurgitation	Retired.
Christine	Female	40-45	NZ European	14 years	Protein S deficiency. Antiphospholipid Syndrome	Beneficiary.

4.2 PARTICIPANT PROFILE

The completed sample size was ten participants. There were four males and six females. Participant's ages ranged from forty-two to eighty-five years of age. All had been prescribed Warfarin by their General Practitioner. Participants had been taking Warfarin for between six months to twenty-eight years. Eight were NZ European and two were NZ Māori (Ngāi Tahu and Ngāi Tau). Four were retired, three working (two in manual employment and one as a professional); three were beneficiaries. Indications for Warfarin included five with atrial-fibrillation, four with mechanical valve replacements and one with Protein S deficiency.

4.3 SUMMARY OF CATEGORIES/SUB-THEMES/THEMES

Data analysis is summarised by the six key themes, which are further divided into sub-themes and categories and presented in Table 3 (see below). The development of themes involved a process of data immersion, with the de-construction and re-construction of raw data, moving from parts to the whole of the transcripts. Through this process interpretation and understanding of the participant's experience culminated in the researcher developing the major concepts.

Table 4: Summary of categories/sub-themes/themes.

	<u>Theme.</u>	<u>Sub-theme.</u>	<u>Category.</u>
1.	Impact.	<ul style="list-style-type: none"> • Quality of life. • Concerns • Change in lifestyle. • Employment. • Travel. • Age. 	Normalcy. Consequences. Adherence. Hospitalisations. Healthcare (cost and quality). Reduced access. Financial. Insurance. Safety/Accidents. Diet/herbal preparations. Alcohol.
2.	Self.	<ul style="list-style-type: none"> • Self-responsibility. • Self-management. • Self-care. • Decision-making. • Self-perception. 	

		<ul style="list-style-type: none"> • Future-focused. 	
3.	Knowledge Acquisition.	<ul style="list-style-type: none"> • Cognition. • Time since commencement. • Integration. • Experiential knowledge. 	Lived with it. Boundaries.
4.	Information/ Misinformation.	<ul style="list-style-type: none"> • Internet. • Hearsay. • Rat poison. • Source of information. • Lack of information. 	Filtering and discernment.
5.	Education.	<ul style="list-style-type: none"> • Presentation of education. • Educational deficits. • Family. • Professionals providing education. • Topics of education. • Timing and Retention. 	Learning modalities. Lack of understanding. Variety of health professionals. Incomplete/hastiness.
6.	Relationships With Health Professionals.	<ul style="list-style-type: none"> • Trust. • Looking for guidance/aiming to please. 	Relationships. Ease of access. Partnership/ Participation.

		<ul style="list-style-type: none"> • Variety of health professionals. • Critical/mistrust. 	Confidence. Inconsistent.
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Developed utilising inductive data analysis (Thomas 2003; Thomas, 2006).

4.4 INDUCTIVE DATA ANALYSIS

Inductive data analysis was undertaken, commencing with transcribing by the researcher. All transcripts were read and re-read in their entirety to gain an understanding. The researcher undertook continuous reading of all transcripts and segments of transcripts moving between parts and the whole to identify categories, sub-themes and themes. Upper level themes extrapolated from the aims were ‘impact’ and ‘health professionals’. Lower level themes were derived from ‘in vivo’ coding and include; ‘self’, ‘knowledge acquisition’, ‘information/misinformation’ and ‘education’. All themes reflect the core messages from participants. An explanation of each category, sub-theme and theme is now explained with excerpts from transcripts to support the findings.

4.5 IMPACT

The first theme looks at the impact Warfarin therapy has for participants. Warfarin needs close monitoring, and impacts on many facets of participants’ lives. The theme of ‘impact’ developed from a question asked during interview and from participants’ own discourse and experience. Although there was an attempt at normalcy and impact reduction, occasionally it was problematic and individuals managed this differently. Impact pertains to quality of life, changing lifestyle, employment, travel, age and finances for participants.

4.5.1 Quality of Life.

4.5.1.1 Normalcy.

Warfarin requires ongoing monitoring and interacts with medication and food, although participants integrated routines to reduce disruption. Cognitive efforts

dissipated with longevity of Warfarin therapy, reducing time and disruption. Nick has taken Warfarin for twenty-eight years and ensured fulfilment of life.

And I kind of took that with a bit of a grain of salt 'cos again, it's like, well do you live your life as much as you can, or do you sort of do everything by the rules and end up potentially having a less than fulfilling life I guess.

Although acutely aware of the need to take Warfarin long-term, Christine contemplates her desire of a medical breakthrough and therefore a discontinuation of Warfarin.

Another tablet would be nice when foods and everything don't affect it, but umm, if those foods affect it, why can't they you know, don't diabetes Type 1 diabetes is it? Is ah diet related and exercise. Well why can't Warfarin be as well. It's well all the foods affect it and they can yeah can affect your blood, why can't they be like your um medication.

4.5.1.2 Consequences.

All participants were aware of the consequences of not taking this medication. These consequences were articulated clearly. There was concern of permanent cognitive and physical disability. Cheryl clearly understands the consequences, which motivates her continuation of Warfarin.

Like I could've had a stroke if I didn't, well I would do go on it so I wouldn't get a stroke, I don't want a stroke. It's horrible thing to happen, it's worse than a heart attack. I mean it CAN be worse than a heart attack. It just leaves you more disabled doesn't it? A stroke.

In contrast, while Richard understands the need to take Warfarin, there is limited cognisance of the consequences. In this excerpt, Richard tells what his specialist said to him about the need to take Warfarin.

His [specialist] explanation was it because it's a mechanical valve and therefore not a natural part of your body, if the blood is not flowing past it, it can decide to congeal around the valve...It's just you stand that risk of it clotting up around the valve. Oh and I suppose it would stop it from opening and shutting properly. I don't know what you do then.

4.5.1.3 Adherence.

All participants accepted the need to take Warfarin and there was long-term adherence. Oversights or forgetfulness were temporary unintentional non-adherence, rather than deliberate omissions. These happened sporadically and appeared related to change in routines as Cheryl describes; “Only because I stayed at the boyfriend’s. And that’s OH NO, I forgot my Warfarin. It’s been a couple of times”. Steve deliberately changed his routines, which were initially detrimental to his adherence. He is now taking Warfarin in the morning to rectify and reduce the impact.

... night was just so confusing, especially when you come home one night oh 4 o’clock a few nights and next night it might be 7 o’clock. ...Oh, there was one day I actually had no idea whether I had taken them or not. It got that, you know, how it’s one of things that you just don’t know whether you’ve done it or not? And I said, I don’t, I had no idea.

4.5.1.4 Hospitalisations.

Two participants had been hospitalised directly related to Warfarin. This was a direct consequence of taking antibiotics and undergoing a surgical procedure and resulted in a cascade of medical interventions. Four participants were hospitalised for other medical reasons. Christine describes her experience:

And then the doctor did my blood test, Oh plus he put me on, the doctor put me on umm antibiotics. Yeah, I had a chest infection. And yeah then he tested my blood levels and it was nineteen. **Amazing.** I didn’t feel; I felt normal. Apart from having the ‘flu. Ha-ha. Yeah, I to go to hosp... they put this, what is it? Some kinda, I don’t know what it was, it was yellow stuff. It was frozen. They had to wait for it to thaw out and then they put a line in and umm yeah, and they put that into me and did blood tests. Yeah, stayed in overnight.

Nick haemorrhaged post-operatively. He is reluctant to go through a similar procedure again because of his previous experience.

I had piles and I had them operated on...and they’re back, so and I’m not going through that again because again I what was it 10 days, 7 days later, I haemorrhaged, I went into hospital. They went through roughly what was it 18 hours of bleeding. They couldn’t stop it, they couldn’t control it. Umm my I forgot which levels they were but they dropped below 80 or 90 whatever critical what was it? Haemoglobin levels. So it all got a bit untidy and I was suddenly pumped with umm and I forget what it is called but supposedly it is

very expensive. I was a white blood product which supposedly is very expensive. Yep and they pumped me full of that and then red blood products and it was pretty horrific sort of an evening actually.

4.5.2 Concerns.

4.5.2.1 Healthcare (cost and quality).

In NZ there are medication subsidies which reduce medication costs. PHARMAC is the controlling governmental body for the contracts for medication. Nick discussed incessant concern regarding PHARMAC changing funding for Warfarin; thereby reducing access to healthcare and increasing personal burden. Nick regards Warfarin as his lifeline.

Ah it also be nice to know that suddenly PHARMAC or whoever don't sort of go ah we're not going to subsidise it anymore and all of a sudden bang, I'm left with you know god knows, \$100/month or \$200/month, or whatever it is going to be to um, you know, have the drug that essentially keeps me alive. That would be a pretty scary thought.

Recently there had been a problem with the bioequivalence of the three milligram Warfarin tablets. These tablets were recalled and Nick explains how this has been problematic and concerning in regard to his ability to manage his INR.

... there was six months ago there were issues with it did go a bit nutty but then there was the drama around umm the actual Warfarin dosages where potentially, had been, not tampered with, but they were you know incorrect coming out of the factory with the wrong dosage, but I'm picking that was what it was. And some of it was recalled...

4.5.2.2 Reduced access.

The ability to access public health within a timely manner directly impacted on quality of life. This reduced autonomy and diminished optimal function. Alan requires a procedure that could potentially increase his mobility. In the competition for finite health dollars this procedure is considered minor. Alan verbalises the impact on his mobility and the interval to access.

But ah I mean I have trouble walking very far, these days because my I've got feet that play up a bit so I've got bunions and bone spurs and things like that and um oh I suppose I could have them fixed but there again I haven't got the, haven't got the money to do it.

4.5.2.3 *Financial.*

There were attempts by participants to minimize the financial impact of taking Warfarin. Ongoing monitoring required continued financial outlay, petrol usage and increased doctor's visits. Increased financial impact was accepted as a consequence of taking this medication. Financially there were varying degrees of impact. If participants were dependent on a government benefit, this impacted on their financial reserve. Miriama highlighted the significant impact of being on an Invalids Benefit, with limited finances. "... because I was using my car, I was using up my gas and blah. I don't get much. It's the Invalids Benefit. It is possible. I said will I need to pay for that. She said 'No' ”.

Alan explains the eventual need to stop seeing a private cardiologist as he was on an annuity and was continually utilising his finite savings “....when you are on a pension any cost is significant and we've got savings; but we haven't got a hell of a lot. And the older you ha-ha get, the less you get. You know, it's you start to use it up”.

4.5.2.4 *Insurance.*

One participant had private medical insurance and he had his operations funded. He was in a position to continue and had no financial concerns. “The operation and everything was paid for by *** [insurance company], bless their cotton socks...We've 100% cover...” (Richard). As the youngest participant and the one who had been taking Warfarin the longest, Nick has felt the continued disparity in attempting to gain health and mortgage insurance. His current mortgage insurance cannot be updated as this is not financially viable, which limits his choice.

I guess the other cost ahh, insurance. You either can't get it or it's loaded significantly um, to the point where it's not worth having. I manage to um when we bought our first house um as part of the deal because it was our first mortgage and all the start. It was like a lump sum, lumps sum payout insurance to cover that original mortgage and that, normally at that stage we are talking about fifteen talking about only fifteen to sixteen years ago.

Other insurances are unaffordable and this burden has significant impact on Nick and his young family. “Um and other insurances I simply don't have because they load the premiums so much it's you know sort of risk sort of um benefit

analysis; it's like too hard". Nick feels insurance companies would avoid payment if he did have insurance, and excuses would be made to link any claim back to his heart valve. The liability of being uninsured is one that he lives with. He feels, financially, premiums would be prejudiced and consequently are unaffordable.

And medical insurance I don't have and that again is that's another thing as I get older and umm and sort of back to the mum and dad when they, they have medical insurance and they just kind of go privately and get it sorted...From a financial perspective, ah and so I never really followed it up more. As I said the loading seem to be you know sort of anywhere from sort of 400% to maybe a 1000%. Just too hard. Yeah and they talk about pre-existing conditions or anything, but you know, I guess you can turn it around the other way. Just about anything you do.

4.5.2.5 Safety/Accidents.

Personal safety was concerning for participants, especially with regard to bleeding and the inability to advise rescuers if injured. Cards or medic alert bracelets were utilised to alleviate worry; nevertheless, this did not stop participants from driving. Alan takes contingency issues in order to protect himself and allay his fears. This gives him jurisdiction and increasing autonomy. "...well I carry it with me [booklet] all the time as they suggest. Because if you had a car accident or something like that, obviously if they found it in your pocket they'd be more aware..." Cheryl has concerns regarding workplace safety after a recent accident requiring medical attention. The consequences of Warfarin intensify her fears.

I'm sort of very conscious more about things. Especially my job [Pointing to arm]. And it was a 7mm GAPING hole, wound they call it... 'cos I didn't even know I dun it, 'cos it was a guillotine it, the only reason I knew is, it actually pulled my top and when I looked it had a big cut.

Nick has adapted to reducing the impact on his life of taking Warfarin, although he still manages to involve himself with all the activities he wants to pursue and enjoy. He has introduced his children to his pursuits and interests and he lives as 'normally' as he can.

I haven't got any other options so it's more I guess it's minimising the impact and that's potentially why I was probably least ahh careful in what I could've have been as a growing teenager and young energetic male....I don't think its affected anything you know, I still riding my mountain bike, not

enough. Play golf, not enough. Surf but not enough you know. All the things I'm trying to get my children into.

4.5.3 Change in lifestyle.

4.5.3.1 Diet/Herbal preparations.

Diet appeared challenging to most participants. Only one participant had not changed anything in his diet and seemed unconcerned to this effect. "No, I've had to change absolutely nothing" (Steve). Interactions between herbal preparations were known and were taken cautiously, with advice. Elizabeth discusses increased vigilance with diet and the disregard for herbal preparations.

... you can't drink grapefruit juice which is my favourite juice... I must admit I didn't really connect Warfarin with diet apart from grapefruit juice and not too many dark green vegetables and things, um so I never really asked about diet, nobody ever mentioned diet to me um except you know the grapefruit juice thing, um so I that I didn't think about that and I don't really take herbal medicine, I feel I take enough medication anyway... if I was going to take anything I would check it out with the chemist, I'm quite cautious in these things.

Linda is aware of numerous interactions and is adapting her diet accordingly. Although the impact has been immense and she feels constrained.

... you feel quite restrictive with the Warfarin as well as that... I think the only real thing I probably miss really would be; I love lettuce and stuff like that and it's and veges and things and yeah. That's probably the main thing and a just a few other you know bits and pieces like that's right. You can't eat cranberry juice. I was going to try green tea, but of course you can't have green tea...

4.5.3.2 Alcohol.

Steve is inconsistent with his alcohol consumption, and was unaware of the interaction. It was only reading through an educational pamphlet during the interview that he realised that Warfarin metabolism is affected by alcohol consumption. "... here's the alcohol [Reading from booklet] 'No more than two standard drinks per day'. Well I had 3 rums last night Christ, does that matter? I haven't changed nothing. Just carried on, just as usual". Nick describes the impact Warfarin had on his formative years and the consequences that transpired through alcohol.

...I went out and had probably a few too many beers than I should of and you know fell over and then got a massive haematoma on my on my shin. And ended up in hospital with that...and then even as I've got older, 'til I was sort of got married and settled down and had children. Then you invariably go out on a Friday or Saturday night and end up and you know drinking more than I should.

4.5.4 Employment.

Three participants were in paid employment. Two were in manual positions and one worked as a manager. With manual employment there was a concern regarding Warfarin as Cheryl previously discussed under the safety theme (p69). Steve is self-employed and avoids certain areas of his work to protect himself, increase personal safety and reduce the impact of an accident or injury. "...there's this hedge, a real prickly bloody thing awful. And I just said I didn't want to do it because it's a big long, it's about 80 metres long, because I don't want to make myself like a pin prickle".

Participants have concerns regarding discrimination from employers if their medical conditions were disclosed. Employment concerns precipitated an unintentional concealment of health information by Nick as he was suspicious this could be detrimental to his future employment opportunities.

...but I don't tell my employers that I have a heart condition. Ahh, especially if they're not asking and you know there's usually like. 'Is there any reason why you shouldn't get the job?' It's not like well, and I know I've got an aortic valve and blah blah blah.

Cheryl has supportive employers and work colleagues and regards ongoing Warfarin monitoring as an opportunity to have 'time-off'. However, she is appreciative of her work environment.

'cos I've got it written on a little board at work and the man opposite reminds me. "You've got a blood test today." Ha-ha... 'cos I don't tell the bosses now I'm going for a; I just let Andrew know, he knows now, and I just go and have my blood test and come back. So I don't have to look for the bosses to tell them.

4.5.5 Travel.

Travel overseas was not avoided, although an attempt by participants to mould the monitoring into their travel and reduce the impact was evident. Although initially verbalising to the interviewer that travel was not a concern, Cheryl later said she rationed the amount of blood tests to reduce financial burden and ceased alcohol consumption while undertaking her cruise.

I was on the cruise for ten days and I went for the first injection [blood test]and it cost me a hundred; I got two, and it cost me \$200 for two blood tests and I haven't got that much money to put on that so I got four about five days and then um they took it, so I only got the two. So I was really stressing out it. I know that it was expensive and having it here, I wasn't paying I didn't have to pay so I was really stressing out about it then on the cruise... so I good and didn't have any alcohol... the doctors' charged whatever they want, so you they can't tell you how much.

Other medication was more of an imposition described by Elizabeth, who altered timing and frequency to reduce disruption, but consequently experienced increased side-effects.

... the one I had the most trouble with travelling was the Frusemide...I would not have to take it in the morning and take it when I came home...So that was the one that I had the problem with. Sometimes I didn't take it at all. With the results that I did get swollen ankles, but that was partly from walking. And um but the other medication I just kept to the routine that I had with that.

Two participants divulged that they did not travel. It was unclear if Christine's lack of desire to travel was related to co-morbidities, memory issues or for personal reasons. "No I don't go overseas. No. I've been to ***. Ha-ha. I think that is about as far as I've got. Yeah, 'cos I don't like travelling anymore, I hate it."

4.5.6 Age.

Chronological age did not necessarily indicate the level of impact on participants' lives. The youngest participant Nick describes not letting the Warfarin dictate the ability to live life to the full. As he matures, he now contemplates the ageing process and ponders his future; with implications of Warfarin-related complications.

...I guess when you get older and perhaps the need to have aging operations, ahh then yeah there is some concern there but it's just going to be more difficult than what it otherwise would be if I wasn't on Warfarin. I had thought about that with getting older and if I'm anything like my parents umm, ah dad's had both knees replaced. Mum's about to get her 2nd knee replaced...And it's kind of like if I have to go through a few operations, it would be easier if it wasn't on Warfarin. You know so they've had backs and legs and knees and all sort of ops so, if it's genetic, then I could be in for a whole bunch of ops which is going to be um you know, it's going to make life a bit more difficult because I'm on Warfarin.

At a sprightly eighty-six years of age; age is no barrier to Elizabeth who independently manages her Warfarin, is knowledgeable in regard to her medications, and is active in her health-related decisions. She lives a socially and intellectually fulfilled life.

I belong to the book group and I belong to a historic society and I go to lectures at the University. I can go to um the Court Theatre and places like that with so, I had to keep on the go, I would get depressed, if I didn't have people to mix with and go out to things...Here I can drive and get to everything I want to...

Health priorities change as people age and extension of life becomes paramount to some people. Alan is clear about his reflection and concludes that he has acquiesced to endeavour to extend his life and conversely the actuality of his limitations.

...as you get older and I'm in a group that you know we're all of an age group, some are a bit younger but um we all sort of coming to the to the conclusion well we've, ha-ha if we want ah um hang around for a bit longer, you go through these things, you put up with it, um what you what you find hard to reconcile with is the that you can't do the things that you used to do you know.

4.5.7 Summary.

The theme of impact has highlighted the influence Warfarin has on participants' lives. It is embedded in their quality of life and diet. It has financial implications and an inability to obtain insurance. The impact of Warfarin therapy has increased the difficulty for participants when travelling and has resulted in unplanned hospitalisations. Participants have concerns, but they are still concordant with their Warfarin regime.

4.6 SELF

'Self' discusses the relationship participants have with themselves. It evolved from a discussion about relationships whereby they do not need any outside influences. The 'self' is determining and autonomous, and this guides them as individuals. Participants were able to decide what would be beneficial or detrimental. Participants processed how decisions correlated to their values and priorities of life.

4.6.1 Self-Responsibility.

Decisions are made with thoughtfulness and self-regard, with the notion of self-responsibility. Nick takes responsibility for himself by explaining that he takes advice, but likes to ultimately make his own decisions. He has self-adjusted knowing the limitations; yet he has the desire of a full life.

There's that kind of that fine line between ah, told you shouldn't do something, ahh and to knowing personally that you know. I kind of, I do know my boundaries, and you know, so that I don't let it, but after being on Warfarin since I was fourteen, you know, I've got a fairly fair idea of what was eighteen years, so of knowing umm you know, what happens and what I can and can't do.

4.6.2 Self-management.

Motivation with self-management increased compliance Participants exhibited idiosyncrasies regarding medication-taking which ensured compliance. Richard documents his regimen in his diary and second checks himself, to increase his confidence and negate doubt. "...I write it in the diary and that's it. I go to the diary at night to make sure I'm right, even though I think I know I am I always check it". Elizabeth ensures compliance using an egg cup. This reduces reservations, enhances memory and maintains independent medication management.

I always get my medication out of the bottle and put it in the little egg cup, so that it's there and I see it and if the egg cup's empty, I've taken it 'cos it's when you take something so regularly every day if your reading or something, it's quite easy to automatically take it and not sort of savvy that you have so I have to guard against such things.

4.6.3 Self-care.

One participant discussed self-management of monitoring of INR. The gathering of information was self-motivated and self-driven. Self-management potentially was seen as an ability to participate in his health and this was emancipating. It also gave self-control, ownership and independence of his Warfarin monitoring and management. Richard had pro-actively and independently sought information and followed this up.

We tend to go to Australia, well we didn't this Winter, but most Winters for at least two months and the thought was should we have a machine then, rather than going to medical centres and are they going to say oh you gotta have a letter and you gotta have this. We don't know. Whereas, if we had the machine, and we could just email the answers back. Also, it would be a chance for us to monitor it closer...so we thought we would probably if we toying with the idea of going to Europe next year at some stage and I think if I went there I'd rather have the machine. Then once again they say you wait for hours and that sort of thing.

4.6.4 Decision-making.

Elizabeth initially declined to take Warfarin. For her, a concern regarding hair loss, the disruption Warfarin monitoring has, and the restriction on diet was influential. She exhibited careful deliberation of Warfarin therapy weighing up the risks and benefits in her decision-making process.

...but I didn't particularly want to go on Warfarin for several reasons, the nuisance of having your blood test every four weeks, actually I don't mind having blood tests but it's the nuisance of having it. The fact that you've had its one is the symptoms thinning of hair... Ha-ha and um also you can't drink grapefruit juice which is my favourite juice.

4.6.5 Self-perception.

The way in which participants looked at themselves was important. This enhanced adherence, decision-making and responsibility and gave an increase self-worth. Miriama has a commanding way of describing her autonomy in regard to self-perception.

... one occasion at the public hospital, I ended up in the heart ward. And these wonderful nurses and doctors came around me and they said "we would like

to try you on Warfarin. And I looked at them and I looked and I said “I don’t want your rat shit”.

4.6.6 Future-focused.

The ability to plan ahead and focus on the future was relevant in all interviews. Participants were continually analysing their life and striving for a future that included Warfarin. Richard could see the benefit of healthcare in relation to improving his health and was grateful he could focus on the future.

We’re pleased it’s done because I don’t know where I’d be now, ‘cos he said [cardiologist] it was getting worse...I had a check a few weeks ago and ahh ***** [cardiologist] said he didn’t want to see me again, so that’s a good sign.

Although her initial exposure to travelling with Warfarin had been stressful, Cheryl was still excitedly planning her next holiday. “...so if I went again I would just stay on the ship, unless it was a different cruise. Our next one’s Italy. It a five year plan for Tania’s 50th”.

4.6.7 Summary.

‘Self’ has looked at participants’ decisions regarding themselves. It addressed their motivation and self-responsibility, self-management and decision-making. ‘Self’ saw the prioritization of self care and future planning after weighing up benefits versus risks.

4.7 KNOWLEDGE ACQUISITION

This theme explores the factors associated with the acquisition of knowledge and will discuss participants’ cognition, motivation and complacency. Placement on the trajectory from initial education did not correlate a relationship to understanding. Although knowledge was acquired, participants were self correcting and may accept or reject knowledge. The acquisition of knowledge may not necessitate understanding.

Christine hopes for the discovery of another medication and makes an analogy with diabetes, to utilise diet to manage clotting levels. This began from a recent revelation of fluctuating INR results and a frustration of the constriction she now felt after learning more about the medication.

Another tablet would be nice when foods and everything don't affect it, but umm, if those foods affect it, why can't they you know. Don't diabetes Type 1 diabetes is it? Is ah diet related and exercise. Umm well why can't Warfarin be as well. It's well all the foods affect it and they can yeah can affect your blood, why can't they be like your um medication. Yeah and you have so much of something a week, yeah that'd be nice.

4.7.1 Cognition.

Three participants freely acknowledged they had memory and concentration issues. Impaired cognition appeared to impact on their ability to process knowledge and therefore understand. Various techniques were utilised to assist memory issues. Christine's mother accompanied her to the interview at Christine's request. The researcher was unaware her mother was accompanying her. Verbal consent prior to commencement of the interview was obtained. Having her mother accompany Christine to appointments is a strategy she utilises to ensure correct information is portrayed and obtained.

Continual reinforcement of information aids understanding. Linda admits to memory issues. Since recently commencing Warfarin she describes feeling overwhelmed with the quantity of information she endeavours to process.

...sometimes I not always remembering stuff and so some I kinda look back through a wee bit of information on it... 'Cos I get mixed up myself and you know, it's new, even though I'm reading it and from time to time...I'm not sure what I have to actually look for. There is so much stuff here. I'm finding my concentration is not good. It wasn't good before, but it seems I've extra stuff on my plate.

4.7.2 Time since commencement.

Participants with newly acquired knowledge verbalised increased difficulty than with those who had long-term experience. Experience was portrayed by increased complacency, incorporating into their life, changing priorities and self-adjustment. Placement was on a continuum and depended on the time that had

elapsed since commencement of Warfarin therapy. Linda recognises the need to continue learning after six months. “But I’m pleased I’m going to this rehabilitation thing because I’m going to learn a wee bit more... So, that’ll be good I can ask questions, and there’s week or two out, they have a dietician and I’m just hoping that to get maybe get more ideas”.

Whereas Nick, after twenty-eight years on Warfarin has integrated and adjusted to suit his lifestyle and minimise interference, so it has become subconscious. “I guess partly because you know dealing with this since I was fourteen, and whether I’m doing it differently than somebody else or not, I don’t know. Maybe I just kinda do it automatically but, I’m not really aware of protecting myself as such”.

4.7.3 Integration.

Taking medication has become such an integral part of participants’ lives. It is something they do without cognisance. Adaptation to taking medication has occurred. Alan depicts his integration of medication into his life. “...in my situation and I can only talk from that, I don’t give a lot of thought to it. But then I don’t give a lot of thought to Betaloc or the others. I take them because *** [cardiologist] tells me to take them, and they seem to work”.

4.7.4 Experiential knowledge.

The knowledge acquired by experience is one that participants filter by accepting or rejecting knowledge as they experience taking Warfarin.

4.7.4.1 Lived with it.

The effect of alcohol on Richard’s INR was explained after he experienced an unusual result when he re-introduced alcohol. He then monitored and explains his thoughts;

...well originally we had quite a hassle getting it sorted and then we sort of got it on the level and I hadn’t been drinking and then I decided right I’m starting to feel like I want a drink now. And that knocked it for a while but then they levelled it. When we came back from up North, it was too high. It was 3.2 or something. So he [GP] said come back in a week’s time. Now

during that week I stuck fairly strictly to, what we perceive as the required things, and it was right back. So that's what makes me think, you know, a week makes a big difference.

Reluctance to change behaviours that are deemed enjoyable is explained by Christine. Even though she has been advised to limit alcohol intake and stop smoking, she has rejected this advice. She perceives no affect by these behaviours, so therefore change is not necessary. "It ain't gonna hold me back. 'Cos they keep telling me, stop smoking you know. You can only have only have 21 beers a week, no 21 cans. No. No way".

4.7.4.2 Boundaries.

Knowledge is not always acquired until boundaries are challenged. Steve acknowledges the need for regular monitoring. However, he became complacent and subsequently experienced the consequences, which was frightening and he rectified his behaviour.

...it was always sort of all right and you take it and you know, and I was sort of, and it never worried me if it was slightly high...you got to take it so it doesn't get, because otherwise your valve could clog up or something, and you'd drop dead I presume. So, I thought a bit of high won't matter too much, it will just run a bit faster. But I think I was wrong. In fact I know I was wrong. Well in my case I know I was wrong. So now I'm quite, ah I'll be definitely never letting it go more than once a month. I sort of had to push the boundaries to find out what they really were.

4.7.5 Summary.

This theme illustrates how participants' acquire knowledge and is related to cognition, memory and the length of time taking Warfarin. Experiential knowledge and testing boundaries facilitated an acceptance or rejection of knowledge, which enabled participant's decision formation.

4.8 INFORMATION/MISINFORMATION

Information was acquired from differing sources and not all information was reliable. Information/misinformation explores the reliability of information. The internet influenced the majority of participants. Nevertheless, there were varying

degrees of trust from information received through this source. Warfarin is known as 'rat poison' and this was commonly discussed by participants. Other people's opinions were espoused to participants, with varying degrees of credibility and this was filtered.

4.8.1 Internet.

The internet proved a resource of information that was easily accessible to nine participants. Christine is reliant on health professionals for resources from the internet. "...you can only get information off the internet and there's no other. And I haven't, I don't. I'm not rich enough to own something like that".

4.8.1.1 Filtering and discernment.

Care with the use of information was shown by participants in regard to the reliability and accuracy of information. Although they did read information, they did not always believe it and information was filtered. Elizabeth explains her use of the internet for information.

I'm not a great looker upper of things like that because I think if you could look up every disease under the sun and you could find the symptoms for yourself... And um practically every medication you take if you read the warning to seniors you'll see that it's got everything like that...but I wouldn't necessarily take the internet's err opinion on a disease for instance for being THE opinion because that Wikipedia of theirs is frequently wrong isn't it? So I'm you know I'm not easily convinced in those ways.

In contrast, Richard uses the internet regularly and unreservedly. He has studied it extensively in order to gain information.

Whereas we're inclined to err, if you taking it I've studied 40 000 websites to see if there's anything there that I should be doing or I shouldn't be doing or things like that. I haven't found out anything that I didn't really, you know, have a handle on.

Other people have accessed information for participants. The websites were not known to participants. Miriama however did believe her daughter's explanation of eliminating liquorice after she searched the internet. She also wanted to share this information with others and ensure the correct information was being portrayed.

She said 'I just found it on the computer that liquorice is not good for Warfarin'. Did you know that? Well, I was taken aback because I love and I've never touched it since. Afraid that it might upset my, ha-ha, tablets. And she found it on the internet somewhere. About Warfarin and about what its reactions were. If you had certain foods or certain things. So I just thought I'd mention that in case you want to tell someone else.

4.8.2 Hearsay.

Participants describe the influence of others. Hearsay was conveyed through lay understanding in regard to others' misnomers or misinformation. Comparing experiences with other people on Warfarin therapy regarding the number and frequency of blood tests was questioned by Cheryl's work colleague. " 'He's about once a month' ...and he said 'but you're having them like every week. I've never known a person on Warfarin to have so many' ".

Significant others have attempted to influence decisions in regard to commencement of Warfarin. Linda's caregiver tried to influence her initial decisions, but her final decision was guided by her surgeon.

Um 'cos Trevor [caregiver] said to me 'oh no you don't want to be on the Warfarin, that's awful and people have side-effects and all sorts of stuff' and 'oh no you don't want to be on that'. So it's almost like a lot of people think oh Warfarin that's not um that's not good and so I kind of was a bit like that myself but then when the specialist

4.8.3 Rat poison.

All participants identify Warfarin being known as 'rat poison'. Participants acknowledge this differently. Various emotions are accredited by participants in relation to this information. Responses range from fear, to interpretation of the number of people on Warfarin, and the sustained use of this medication. Elizabeth is unperturbed with taking Warfarin even through the knowledge of it being administered to rats. "I know it's a sort of a thing of like rat poison contains it doesn't it? You know if you; anybody you tell you take oh they say that's 'rat poison yes'. Yes I know it's rat poison".

Miriama acknowledges that she initially declined Warfarin because she thought it was a poison. Miriama considers misinformation and rumours as detrimental to Warfarin initiation and acceptance. Miriama believes people may therefore misinterpret the requirement for Warfarin. She verbalises a lack of knowledge about what is in the medication.

... I didn't want to take it to start with because I'd heard rumours. Now those rumours have got to stop. I don't know who the hell put it out about rat poison in it. And that's something that I don't know what's in it. I don't know really what's what is in it, but I'm not that particularly worried, it's just doing its job.

4.8.4 Source of information.

After Warfarin is initiated information is received from a variety of sources and health professionals. Participants received written resources, a video and websites. Information was presented individually or in a group, by health professionals or people whose discipline was unknown.

Nine out of ten participants have a 'red book' which is produced by a drug company (GlaxoSmithKline, 2011) which provided documentation and basic information. Ann finds it beneficial, "The little book they give you when you go onto Warfarin. That was quite helpful really 'cos it explained quite a lot. Yes I saw a little video about it, which was good". Although Elizabeth reads the information provided with medication she is cautious of too much information being provided. "Well, there's a whole lot of err information came with the tablets, you know those things if you read them, there's so many warnings of what can happen you."

4.8.5 Lack of information.

Others state they received no information, they feel they did not receive enough to be able to understand and manage independently. "I don't think so no, our only gripe if that's even the right word to use, is the lack of information, the lack of preparation" (Richard).

4.8.6 Summary.

The theme of information/misinformation has elucidated the information participants received was obtained from a variety of sources. The internet played a considerable role in this. Internet information was filtered by the majority of participants. Information obtained from lay people was perceived as beneficial and detrimental. Myths associated with Warfarin known as ‘rat poison’ was scaremongering and anxiety-provoking for some, but disregarded by others. There was an ongoing perceived lack of information and a desire to obtain more.

4.9 EDUCATION

‘Education’ developed from a question asked to all participants at interview. With the complexity of a medication like Warfarin, education is integral to ongoing understanding for participants. ‘Education’ explores the experience of initial education and participants’ recommendations for educational improvements. It will highlight the range of people involved in teaching and the topics covered, as well as how this is retained. The acquisition of knowledge has previously been discussed under a separate theme.

4.9.1 Presentation of education.

Education was presented in a variety of ways, utilising differing formats, and was inconsistent. Information was often conflicting and therefore left participants confused. Linda explains her lack of initial education and the inadequacy for her, of the differing formats offered. “She did talks on Warfarin before and afterwards and you could ask her questions; she did want me to see her and stuff, but I wasn’t well enough to...it was a group session before I had the operation, it was a video sort of thing...” Whereas Christine’s experience was contradictory to this; “No there was nothing. They just give you the prescription there you go, yeah take it”.

With education fundamental to ongoing management, conflicting education diminished credibility. Richard explains confusion after two conflicting explanations.

...we talking to one nurse or somewhere and they said 'oh we always have trouble with these at the start of the asparagus season'...we mentioned to another nurse and she said 'no that doesn't have any effect.' I thought well, obviously somebody doesn't know what they are talking about.

4.9.2 Educational Deficits.

There was recognition by some that there was a knowledge deficit and a desire to increase knowledge. Ann continually ponders taking Warfarin long-term. "...but I think I should've asked about um you know if there are some long-term effects. However, they have someone talking about the medications and all that. So, that'll be good I can ask questions". Miriama still has unanswered questions, which includes why she needs Warfarin. "I would like to ask them. Why are you giving it to me? For what reason and for how long?" Christine acknowledges an educational deficit in retrospect. She has recently been given educational resources.

Nothing. I just took it. Yeah I didn't know nothing until ahh frig, ha-ha, last year was it, that garlic affects your Warfarin...green leafy vegetables. I've always known that medication, that certain medications I ain't allowed. Yeah I've got all of those fact sheets in there on what you're not allowed and that.

4.9.3 Family.

For some education was regarded jointly, with family members encompassing the educative process. Education was integral in management and understanding within the family unit. Richard and his wife work in partnership to support each other. This is evidenced by the use of 'we' in explaining education. "We've sort of learnt that from us or from other people or from the internet". They have concluded together, after discussion and experience, their summation of the education they received. "The whole education, but the education over the whole thing, it's not only the Warfarin, but, it's the whole thing isn't good. We didn't feel".

4.9.4 Professionals providing education.

A range of people initiated education, and this transpired in primary and secondary care. Education was initiated by nurses, doctors, pharmacists and others, whose designation was sometimes unknown. Richard describes where education originated from "Only the nurses were the only ones that said". Education was not necessarily given in one block. Participants accrued knowledge in small fragments,

which added to the complete picture and was not necessarily sequentially obtained. Richard acknowledges advice given to him. “He [surgeon] didn’t give us much; he said about the Warfarin. He said ‘you don’t adjust your lifestyle to suit the Warfarin; you just adjust the Warfarin to suit your lifestyle’ ”.

4.9.5 Topics of education.

Although participants regularly monitored their Warfarin, they received differing education regarding diet, alcohol and side-effects. In retrospect Richard can see the deficits he had in regard to dietary management, “I think the dietary thing isn’t really it’s emphasised as much as maybe it could be”. Nevertheless, he acknowledges the warnings given regarding herbal interactions; “No. We were actually warned not to use, try herbal preparations weren’t we?”

Although previously educated about alcohol Christine explains why she has not changed. “It’s never affected me before. What’s the difference? Things have changed but I don’t think it’s what I do. I was OK before, it’s not that...”.

Cheryl acknowledges awareness of care with medication and that some interact with Warfarin “I take Diclofenac, ah no I don’t. I used to... But Dr *** [GP] said that would make me bleed more, so he took me off it”. Education involving diet and green leafy vegetables was known by most participants as Ann explains, “some foods you have to watch like um a lot of greens and that”.

4.9.6 Timing and Retention.

Participants with mechanical valve replacements verbalised stress related to preparation for surgery. The hastiness in which education was presented did not facilitate retention. Linda explains how her initial education was not conducive to retaining information.

...she did talks on Warfarin before and afterwards and you could ask her questions; um and I and she did want me to see her and stuff, but I wasn’t well enough to. Umm when I went there um I got crook and that...it was a group session um before I had the operation, it was a video sort of thing...they had a team of Doctors and stuff and often um they have different ones but everything’s happened so quickly.

Steve highlights the speed of discharge post-operatively was not conducive to education and feels deficient. He explains his lack of understanding led to a potentially catastrophic experience.

I was out in two days so you had to be quick. I didn't get any information and I think...you're more likely to be fed misinformation than information...I think I'd like to know the reason it has to be between two and 2.5 and the consequences of going under, which I did probably tend because it had to be thin enough to through ya to, and but more importantly the consequence of going over, because I don't think that was mentioned, well I it wasn't mentioned by anyone and I've found that out by a pretty painful experience.

4.9.7 Summary.

This theme has discussed participants' experience of education. There have been differences in the presentation and format of educational materials. Numerous professionals have presented education with a variety of subjects and no uniformity. The preparation for surgery has influenced the educative process and retention. All of these factors contribute to knowledge acquisition and understanding.

4.10 RELATIONSHIPS WITH HEALTH PROFESSIONALS

The final theme presented is in regard to participants' relationships with health professionals and how the participants talked about this topic. This was not directly elicited by me but was a recurrent theme emerging from participants' experience of Warfarin therapy. It seemed that certain relationships were of importance. There was the need to please and take guidance from health professionals as well as relationships with different health professional disciplines. However, there was also a degree of mistrust, scepticism and criticism.

4.10.1 Trust.

It became evident in the explanation participants gave of their experience of taking Warfarin that they trusted health professionals. They described a relationship with health professionals where they relinquished some control, while respecting their knowledge and actions to ensure that their life was enhanced and recognition that they needed assistance from an expert. This was their life and they were entrusting health professionals to do the best for them. "BUT I have a lot of trust, in

my GP, very much. My GP, my nurses, the people that come here to give me my blood tests. I have a lot of trust in them. 'Cos it's my life in their hands'. (Miriama).

The relationship with health professionals also gives reassurance to reaffirm what they are doing is correct, and aids in the continuation of this medication. Ann describes her uncertainty, yet fears were allayed with the reaction of a nurse through non verbal cues. "Yeah, I think I said to the nurse when I was in hospital, it sort of makes you wonder about all the different medication how is. BUT, she didn't seem concerned so [pause] yeah".

It is apparent that participants' long-term relationships with health professionals ensure respect and trust, and enhance their thoughts behind what they think of the health professional involved. Respect and trust increased participants' confidence in health professionals' decision-making and ongoing care. "... as I say *** [cardiologist] had explained why in my case he was doing it, ah which I was quite satisfied with. I mean I've got a lot of respect for him to, and a lot of faith in what he does" (Alan).

Trust is also evidenced by Richard, who expressed confidence in his General Practitioner (GP) and the management, care and time that was spent with careful deliberation of the ongoing management of his healthcare. The GP has also shown in the past to be a sound clinician and his actions have increased Richard's confidence. The GP treats Richard with respect, inclusion and explanation in the decision-making process."So no he's, *** [GP] damn good. *** [GP] thinks everything through and works it through and he's got he's, yeah. We're confident in what he's telling us and how he's treating us. No doubt about that at all".

With trust in health professionals there was an ability to work in partnership. Decision-making could be negotiated regarding ongoing management. Trust was apparent with Elizabeth, who discussed ceasing an antihypertensive medication because of side-effects and negotiated to stop but be monitored. She trusted that the doctor would advise her and monitor her as she came off the medication to ensure safety.

Um when I got fed up with the beta-blocker that I was taking, the Diltiazem which I felt was the cause of all my problems, dreadful constipation, swollen ankles. I said to Dr *** [GP] that I wanted to go off it and I'd rather go without a beta-blocker than have these side-effects. And he said 'All right. Stop then. And you can just come down and have your BP monitored' um every sort of I think it was every four or five days.

4.10.2 Looking for guidance/Aim to please.

Although decision-making was in partnership, there was advice given by health professionals, and guidance sought from participants to assist decision-making. Decision-making involved whether to initiate Warfarin therapy to having a 'pig' or 'mechanical' valve inserted. The thought of Warfarin therapy disturbed some participants, and while they initially declined to commence, after discussion with trusted health professionals this decision was reversed.

And I didn't want to try it at that time. I didn't want to try it. But they [cardiologists] said it would improve the function of my heart. Ah so I come back and I told my family doctor. I said 'Do you know what they want me to do?' 'Well Miriama', and this is ***, my GP. 'Well Miriama, I advise you to take it'. I said, 'Do you? All right'. So I have been on Warfarin.

Decision-making was a heavy burden, not only for their health, but to ensure that they concurred with specialist's recommendations. There appeared to be a tension between making a choice, what was to be of personal benefit to individual participants, and aiming to please the specialist. Linda sums this up with her description about what valve replacement to have. "I had a thing where I could choose whether I wanted a pig's valve or a mechanical valve. And I chose the mechanical valve and the specialist is pleased, 'cos he advised me to have a mechanical valve".

4.10.3 Variety of health professionals.

Participants came into contact with a variety of health professionals. The relationships were dependent on the depth and time participants were in contact with differing disciplines. Allied health professionals were used as sources of drug information. "I asked the chemist and he said, the next day he sort of said ah no, and it wouldn't sort of matter once, like that .And the chemist down here he's quite young, but he's very good. He's very helpful" (Ann).

Participants spoke of an eagerness to learn; an acknowledgement that health professionals knew the information that could assist them, but that they did not receive this from the source they expected. The ability to utilise a personal friend's knowledge, who was a physiotherapist, was more beneficial to Richard than their experience in hospital.

See the, you saw very little of the physio's in the hospital. Even though they said they would have you out everyday walking and all this sort of thing. They took me walking once. Ahh and exercises and that, they did very little.... And we were lucky because we know a physio who happens to specialise in that area and she came 'round a couple of weeks later just to visit us and to see how I was and I learnt more from her in half an hour than I learnt in the hospital. 'Cos I was getting aches and pains and she was showing me how to identify them, and you know work out how things were and what to do. And that that was more help.

4.10.4 Critical/mistrust.

Although there was trust and respect, there were also some negative experiences. Participants filtered information, decided whether they regarded the information and relationship with health professionals to be appropriate and in unison with their own values and expectations. Christine did not believe the original diagnosis given to her and she questioned this with a specialist. She and her family felt that there was another explanation and diagnosis; she continued to question the diagnosis, and felt the need to pursue an alternative.

Dr *** [neurologist] yeah, he yeah he goes no you haven't had a stroke, it's just migraines. It's like no, I don't get headaches. I never had a headache. I didn't even have a painkiller in the house. I mean, Melanie's [daughter] Paracetamol. I didn't have any painkillers, I never ever needed them. Yeah, so it's no, it's not a headache. Mum's arguing with him. It was a stroke. That what mum was telling him and yeah, he ended up doing an MRI 'cos of mum arguing with him, ha-ha. Yeah and they found the scarring on the brain, but I just got a 'phone call saying that I had to go back and have another one. And yeah then we had another appointment to go back and see him.

While in hospital some participants described a feeling of neglect, an inconsistency of ability between nurses, that they were too busy, and that there was not enough care and attention given as would be expected. There was verbalisation

of incompetency and inefficiency which led to a loss of trust and concerns regarding safety.

In the end the nurse said that she would put in a catheter. Which she proceeded to do, stuffed it up completely. She put in the wrong size, and ruptured my urethra, so there was blood everywhere.....I think I can recall somebody, once again it was the nurses in the hospital who were pretty erratic. You know, sometimes they'd start telling you something and then they'd wander off and they'd never come back and finish it and things like that. And they came to take one of the stitches out. The girl got called, she got me all ready to go, lying there with the tray and everything to ... she got called away five times while she was doing that job. Here's me just lying there, oh somebody down the ward would be calling her name and she'd be away or somebody needed a hand with something else and that aw 'Hello' I'm obviously second class here. (Richard).

4.10.5 Summary.

The theme of relationships with health professionals has highlighted the trust, confidence and guidance that are sought from participants in relation to their ongoing healthcare. Participants also aimed to please health professionals. There was a variety of differing relationships with many health professional disciplines. The majority were of a positive nature, however, there were some experiences that were criticised and did not meet expectations and led this to mistrust.

4.11 CONCLUSION

Chapter four has discussed the findings extrapolated from an inductive data analysis. An inductive approach concluded in the presentation of six themes. Impact transcends all aspects of participant's lives; while adaptation and management are utilised there are ongoing concerns. Participants have a regard for themselves and this is influential in their decision-making processes. Although three themes were similar they were separated to better explain. Knowledge acquisition was related to personal ability to understand and retain knowledge. Knowledge was acquired but this may not necessitate understanding. Knowledge acquisition was influenced by cognition, experience and time taking Warfarin.

Information/misinformation is the gathering of information from differing sources by participants. Some information was specifically sought; other information was forced onto participants without request. Not all information was correct or credible. Information included the internet. Information was from differing sources and was not necessarily reliable. The internet, other people and misinformation were influential. Education specifically examined the formal process of receiving initial education and the lack of preparedness participants verbalised. Education was presented to participants in different ways, from a variety of people and on a range of topics. Educational deficits and reduced retention were verbalised. Finally, participants discussed relationships with health professionals. Predominantly confidence, guidance and trust were exhibited, although, there was also criticism and mistrust of others. The findings were interrelated and overlap, however were separated for explanatory purposes. The next Chapter will present a discussion and interpretation of the findings.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

The patient's experience of taking Warfarin within a community setting has not previously been researched in NZ. The only literature to date has incorporated a patient's point of view from an elderly perspective, with atrial fibrillation in a hospital setting or in a Canadian Primary Care facility (Bajorek, et al., 2006; Dantas, et al., 2004). Many studies have portrayed health professionals' point of view and opinions. Chapter five discusses the findings of this study extrapolated utilising an inductive approach. Initially the impact on participants, the altered quality of life and how this was maintained is discussed. Participants' experienced discrimination when seeking insurance coverage. The introduction of Warfarin therapy involved a change of lifestyle. Warfarin therapy impacted on all participants no matter what age. As priorities change throughout life for the participants, impacts also altered.

Chapter five then proceeds to discuss 'self'. 'Self' is a major concept which the participant's experience revealed. Participants exhibited self-responsibility, with care and concern. Decisions were made with cognisance to protect and enhance their lives, while keeping themselves safe. Māori health perspectives are discussed and how this connects to family. Tension arose from participants' external image, where Warfarin therapy was invisible to others, to an internal struggle, where they personally were self-aware. As they adapted to a new 'self', an altered self-image and identity evolved.

Education was inconsistent, generic and inadequate. Education was not individualised to participants' learning styles and literacy levels. Knowledge acquisition may not necessitate understanding. Knowledge was gained through several mediums, rather than just educational sessions by health professionals. Participants also gained knowledge and personal understanding through experience.

Information was not always reliable. Information from internet access exerted an influence which required discernment from individuals regarding its accuracy. Myths and hearsay led to misinformation. Warfarin is known as ‘rat poison’ which added to confusion, anxiety and misunderstanding. Individuality was apparent, whereby individuals quest for depth and amount of information and understanding differed. Health professionals educated participants, but they are unable to comprehend conceptually the experience on participants’ lives. My study has uncovered that there is not a collective experience; but numerous individual experiences.

Health professionals were analysed by participants. Trust was an important component which participants valued in a therapeutic relationship. Mistrust was evident from paternalistic attitudes, which led to disempowerment and unequal power differentials. Relationships with health professionals were increasingly valued if partnership was a priority.

Primary Healthcare is pivotal as it incorporates individuals through communication, continuity of care, sustained access and advocacy. Inconsistency with Warfarin management is exacerbated by no standardised guidelines, with diversity and variance between practices. Doctors, with medication knowledge are seen as powerful. Nursing roles were invisible, even though nurses had regular contact with participants. The development and expansion of nursing roles in PHC to Warfarin education, monitoring and management has potential to improve outcomes for patients. Pen-ultimately, this chapter discusses the limitations and strengths of this study. Finally, Chapter five concludes by highlighting the main concepts discussed.

5.2 IMPACT

The impact of taking Warfarin effected participants individually. Everyone spoke of the impact in differing ways.

5.2.1 Quality of life.

The overriding desire to obtain normality and thereby sustain quality of life was dominant. Normalcy was obtained by 'fitting' Warfarin into their lives, with personalised routines and idiosyncrasies. A new norm developed with time, and cognitive efforts regarding management dissipated with length of time on Warfarin which Wyness (1990) supports. Webster et al. (2011) highlight the personalised routines developed to incorporate and adjust this medication into their lives.

Although participants resigned themselves to long-term Warfarin therapy, there was still a yearning to return to the past, with hope regarding a medical breakthrough or diet control. Ann supports this by explaining, "Yes it would be good to get off it, but I can't see that happening really...but you never know there's, they discover things all the time don't they?" Warfarin is a complex medication that is restrictive. Warfarin therapy necessitates adjustments by participants, requires routines, treats recognised medical conditions, reduces the risk of complications and impacts on quality of life. Webster et al. (2011) supports that Warfarin differs and is unique when compared to other medications. Dowell and Hudson (1997) recognise adjustments are made pertaining to length of time, familiarity and knowledge of medications. This study adds to the understanding of the impact on lives, adjustments and restrictions experienced by patients and the hope of returning to a prior normality.

Travel, while still undertaken, was flippantly regarded as bothersome. There was incongruence with behaviour, as discussion revealed travel impacted on those that had experienced it. There was an increased burden to ensure monitoring, medication and personal safety. Increased financial burden of travel led to stress and alteration of lifestyle and enjoyment. Budgeting was required and there was reliance on contact with PHC to give trusted advice. This study is the first to discuss the effect of travel on participants.

5.2.2 Consequences.

The potential consequences of not taking Warfarin were well known to participants. Awareness of consequences assisted adherence. Webster et al. (2009) agrees and adds this is because Warfarin is a unique medication. Bajorek et al.

(2009) and Dantas et al. (2004) portray decisions to initiate Warfarin was from doctors, with minimal patient involvement, which also corresponds to my study. Nick describes his experience; “I haven’t got any other options, so it’s more I guess it’s minimising the impact”. However this study adds to the impact this has on participants and the lack of choice they felt.

5.2.3 Concerns.

Concern with day to day management dissipated over time. As participants become familiar and more knowledgeable with Warfarin, their concern reduced, which directly correlated to several studies (Dowell & Hudson, 1997; Webster, et al., 2009; Wyness, 1990). The financial burden was essentially viewed as incidental when discussing the ongoing incremental costs of medication, INR testing and increased frequency of doctor’s visits.

The inability to obtain open access to health, mortgage and travel insurance had a significant impact on their personal burden and increased liability. Discrimination was experienced with an inability of timely access to surgery and an inability to gain financially viable or competitive mortgage insurance. Younger participants experienced an increased impact in their ability to obtain or afford mortgage insurance, adding to the personal burden of supporting a spouse and children. Nick explains his experience of mortgage insurance; “...that normal insurance would have cost \$30 and that costs \$100 a month”.

There was a sense of frustration and suspicion regarding health insurance which severely restricted choices, reduced independence and increased financial and personal burden. Insurance companies were perceived as prejudiced and discriminatory towards Warfarin therapy, and potential claims regarded as accountable to pre-existing conditions. Nick explains his experience; “They could probably say well that’s actually Warfarin-related. Well if it’s anything to do with bleeding then bad luck”. This adds to current knowledge as literature does not discuss participants’ experience of obtaining insurances or the financial and personal burden experienced.

Participants' impression was that the future posed reduced access and inequity of healthcare. There is an increasing move towards private medical insurance and an inability fiscally of government to maintain a consumer-focused and driven healthcare system. Participants perceived discrimination in their ability to access, as well as an increased burden of healthcare. With an inability to afford private insurance, or lack of access to the publically-funded health system, this raises issues of quality of life, lack of choice, reduced access and increased financial burden. Alan explains; "I'd be about 175 by the time I got in on the public system". There has been significant developments through the PHCS (MoH, 2001) to improve access and equity of healthcare within PHC. The participants' experience is judged on their ability to access secondary healthcare services and the discrimination of private health companies to cover pre-existing conditions. There is no literature that discusses patient perception of discrimination and access to insurances, therefore this study adds to knowledge.

5.2.4 Lifestyle.

Individual personality traits and experience influenced conformity to diet and alcohol. The socially constructed relationships humans encounter are integrally linked to food and alcohol. Societal pressure to conform creates tension within individuals who take Warfarin. Social restrictiveness is an impact which is likely to see digression by individuals who pursue acceptance. The enormity of dietary impact relates to participants' correlation and knowledge of dietary influences of Vitamin K on Warfarin. Cheryl was still unaware of dietary interactions; "Is there, should you not take certain foods?" Literature agrees with the direct correlation between dietary Vitamin K and its influence on INR measurements (Best Practice, 2007; Harrison, 2008; Holbrook, et al., 2005; Rombouts, et al., 2010).

Alcohol consumption has similar impact to diet. Recognition of alcohol's influence on INR was not understood or disregarded by some. Alan is unaware; "Yeah we have a drink every night. Both of us, so that's one of the few relaxations we've got left". Others were aware and adjusted Warfarin dosage in relation to alcohol intake. Although many consumed alcohol, it was with caution. Campbell et al. (2001) agrees alcohol complicates management and safety, so awareness of alcohol's effect on INR is essential. Harrison (2008) adds that small consistent

amounts of alcohol have a negligible effect on INR. However, Best Practice (2007) includes the lack of control of INR with changing amounts of alcohol.

5.2.5 Medication/complementary medicine.

Participants were cautious using any medication as they were aware of potential interactions, this included over-the-counter preparations. Caution refers to a heightened vigilance, care and protection of 'self'. There was agreement that advice was sought and any avoidance or usage was in direct relation to expertise from health professionals. Literature concurs caution with addition or deletion of any medication (Feldstein, et al., 2006; Freedman, 1992; Harrison, 2008; Hirsh, et al., 2001). They support this study agreeing caution is essential as all medication interactions are multifaceted. The elderly especially as they have increased co-morbidities and poly-pharmacy (Erban, 1999; Ranta, 2010). The experience of a new medication has a profound impact. Participants initially had feelings of being overwhelmed and restricted, which is supported by Kumar et al. (2011) and Neame and Hammond (2005).

Caution with conventional medication also disseminated to complementary medicine. Advice was sought about the safety of combining medicines. Elizabeth asked about complementary medicine interactions; "I would never take anything without consulting the chemist to make sure that it wasn't interfering with what I was taking. But no I don't take anything herbal". This disagrees with the literature that suggest misconceptions that herbal medicine is 'safe' and does not interfere with conventional medicines (Ramsay, et al., 2005; Smith, et al., 2004). This study adds that participants were experienced and knowledgeable of the influence of Warfarin on any medication, whether it is prescribed, over-the-counter or complementary.

5.2.6 Employment.

Variance in employment arrangements culminated in differing impact. The variance of age and employment within this study has given an insight into perspectives not voiced before. Self-monitoring of Warfarin is noted in literature as increasing independence which aids employment (Fitzmaurice, et al., 2005). However, participants' outlook relating to employment has not been discussed.

Self-employment gave greater control and empowerment to allow dangerous activities to be avoided. Supportive employers were evident and were occasionally exploited with behaviour of taking time off for Warfarin-related appointments. Increased personal burden through perceived discrimination and prejudice leads to concealment of medical conditions if pertinent information was not requested. Nick highlights his strategy for employment; “I don’t make a habit of; I don’t hide it as such, but I’m not proactive in telling them either”. The necessity to work is not only to provide for one’s family, but is linked to self-determination, self-worth and enjoyment of life. Fear of discrimination and unequal employment opportunities is associated with employer’s knowledge deficit and misunderstanding; which potentially could be detrimental to obtaining employment as well as advancement of career prospects. This study highlights the potential for prejudice by ill-informed employers, yet also highlights allowances made by altruistic employers. Warfarin impacts personally and financially, with societal pressure and expectations to work. Employment relates to ‘self’, representing an individual’s contribution to society, providing financially for their family, autonomy, self-esteem and identity.

5.2.7 Age.

Warfarin impacted all ages to varying degrees. Advancing age sees increased acceptance and desire to ensure longevity of life. Older people have been extensively studied in regard to Warfarin therapy, and they demonstrate Warfarin impacts on their lives (Ranta, 2010). Younger participants are interested in living a full life that includes sporting and social pursuits. Some are potentially dangerous as Nick describes. “I crashed my mountain bike in what they call a kamikaze race...and yeah lost control and ended up getting a massive haematoma in my femur”.

Focusing on the future is apparent at all ages. Life’s developmental milestones ensure an attitudinal shift that envelops concern over the future. Initiation of Warfarin therapy is personally perceived in relation to risk versus benefit. Cheryl is aware of the consequences; “Dr *** [GP] said I was a candidate for a stroke” and Elizabeth, the oldest in the study, is equally as concerned; “the uneven beating of the heart with the clot and my possibility of a stroke...you know who wants that, so I’d rather take anything than that”. Age was no barrier to self-management or knowledge acquisition. Age did not discourage ownership in decision-making or

control. Ranta (2010) agrees Warfarin impacts on older people and dilemmas ensue with increased complexities of multiple co-morbidities and poly-pharmacy. This study disagrees with Bajorek et al. (2009) and Dantas et al. (2004) who found doctors made decisions on initiation of Warfarin. This study adds to current knowledge by revealing that participants were included in decision-making processes and declined initiation of Warfarin therapy originally. Although they still respected the doctor's expertise they were exhibiting control over 'self'.

5.3 SELF

'Self' is a central theme that resonates throughout all tributaries of this study. Self-perception is important and integrally linked with body image and identity. Reduced life choices limit a person's ability to be autonomous and independent, which leads to an acceptance of a new 'self'. There is tension between an external control of Warfarin versus an internal struggle adjusting to being a Warfarin-taker. Self-management is a strategy that enhances control.

5.3.1 Self-responsibility.

Self-responsibility includes actively participating in their healthcare. Education and knowledge assisted participants to be autonomous. Christine explains self-responsibility to prescribed medication; "and I said I'm not taking this until I find out what's wrong with me". Britten et al. (2004) espouses that patients do not necessarily always have similar views to doctors regarding medications. Kumar et al. (2011) and Neame and Hammond (2005) augment decisions regarding medications are complex. Understanding and knowledge is essential for people to make sense of medications (Pound, et al., 2005; Webster, et al., 2009).

5.3.2 Self-care.

A person's sense of self is to protect and care for one's own rights and safety which was evident within this study. Participants exhibited a desire for self-control, ownership and independence. Literature discusses power-sharing evidenced by patient needs and beliefs being congruent with health professionals (Kraetschmer, et al., 2004). An example from Miriama refusing Warfarin from specialists, but

acceptance from trusted PHC doctors was emancipating. “And I didn’t want to try it at that time. I didn’t want to try it”. Disparately, self-control is diminished with lack of choice in healthcare decisions as evidenced with the necessity of an artificial heart valve and Warfarin. Expertise from specialists in this context was accepted. Britten (1994) integrates the tension exuded to conformity if patients and health professionals’ views are dissimilar.

Experiential knowledge and ‘testing out’ enabled participants to exert self-control. Through experience participants tested their ability to control and not be dictated to by Warfarin therapy. Exerting control is a desire to obtain normalcy and ‘fit’ the medication into their life and routines. Although experiential knowledge and pushing boundaries was beneficial, there was potential for adverse events brought about by lay beliefs, misinformation and misunderstanding. Desire to exert self-control was not replaced by disregard for safety. Steve explains ‘testing-out’. “Well in my case I know I was wrong...I sort of had to push the boundaries to find out what they really were”. Dowell and Hudson (1997) describes testing as distracting the need for medication, a form of control, which is evidenced by denying or reducing the emphasis on illness, or reducing medication. Complications of Warfarin therapy of death, disability and functional deficits are documented by Fang et al. (2009) with tools to assist reducing bleeding risk (Pisters, et al., 2010; Ranta, 2010) which are regulated by health professionals. However, this study broadens knowledge to incorporate participants utilising self-control.

5.3.3 Decision-making.

Safety was paramount in regard to self. In order to maintain autonomy and independence participants exhibited careful deliberation of the risk versus benefit of Warfarin therapy. Participants are increasingly likely to exhibit safety which contradicts Kraetschmer et al. (2004) who found ‘blind trust’ being exhibited by females, people with minimal education and over sixty-five year olds.

The anxiety around haemorrhage risk was highlighted through discourse. Safety concerns altered with age. When younger, decisions were contrary to safety. Engaging in a range of high risk activities pursued by many compatriots in order to live a full-life was essential. Nick explains; “I went out and had probably a few too

many beers than I should of and you know fell over and then got a massive haematoma on my on my shin and ended up in hospital”. Webster et al. (2009) agrees decision-making relates to social constructs, such as the interference of sport, leisure and social roles.

The indications for Warfarin restricted and limited choice, with Warfarin therapy compulsory for participants who had artificial heart valves to reduce actual risk. However, there were delays in decision-making for initiation of Warfarin in participants who had atrial fibrillation and hyper-coaguability which potentially reduces risk. Warfarin is beneficial to patients for stroke prevention, although dichotomously there is a risk associated with the potential to haemorrhage. Literature agrees that the risk versus the benefit needs to be calculated on an individual basis (Dudley, 2001; Fang et al., 2007; Ranta, 2010; Westaway, Cruickshank, Roberts, & Esterman, 2010). The complexity of prescribing Warfarin needs careful consideration in conjunction with patients and their healthcare providers of the risk versus benefit before initiation.

Participants were aware that cessation of Warfarin would have clear consequences. Stack et al. (2008) and Webster et al. (2009) support increased medication adherence with increased consequences. My study contradicts Dowell and Hudson (1997) who extrapolate non-adherence was evident even with known fatal consequences.

5.3.4 Māori Health.

Awareness of Māori health perspectives is essential for all health professionals. The integration of The Treaty of Waitangi and cultural safety into practice assists health professionals to understand the history of Māori health, and the transfer of power that has marginalised Māori. This is evidenced by current poor Māori health statistics (Reid & Robson, 2007) and the disparity of burden of the disease (NZGG, 2003). Māori represented within this study endured the burden of disease, which is congruent with evidence (Ajwani et al, 2003; NZGG, 2003).

Operatively, active involvement in their own healthcare was evidenced utilising tenets of Māori health explicated by the one of many models, Whare Tapa

Whā. Four fundamental concepts of health are intrinsically linked to provide health. These are spiritual health (Te taha wairua), mental health (te taha hinengaro), physical health (te taha tinana) and family health (te taha whānau) (Durie, 1985; Rochford, 2004). Miriama explains her acceptance “I’m quite positive in what is happening with my, with what I call my ‘*tinana*’, my body”. There is a relationship whereby health professionals become an extension of whānau and an acceptance that they are integral in assisting improved health as Miriama explains; “my GP, my nurses, the people that come here to give me my blood tests...’cos it is my life that’s in their hands and if I agree with them, yes”. There is participation, partnership and protection of a Māori viewpoint of health.

Adaptation to a European epistemology is required and an integration of beliefs is crucial. The principle of Mauri, the life-force, is joined to every living thing (Ka'ai & Higgins, 2011; Williams, 2011) and regards blood as sacred. Adaptation is necessary with Warfarin therapy as this is an essential component of ongoing monitoring and safety. Māori have adjusted their holistic viewpoint to incorporate European models to improve their health, yet still having control over their beliefs. This study adds to knowledge by evidencing poor Māori health, but an attempt by health professionals to incorporate their beliefs into healthcare. Māori have control over their own health from their perspective which is imperative.

5.3.5 Self-perception.

Change in self-perception produced a changed self-image, consequently a ‘new self’ evolved as a result of either an inner harmony or turmoil. Tension exists between their external image, where Warfarin therapy is invisible to others, and internally, where they feel manipulated by Warfarin. An emergence of a new ‘self’, one that is a pill-taker evolved. Regarding themselves as a pill-taker restricted by rigid routines, diet and monitoring, affected self-identity. Social interaction is intrinsically linked to diet and alcohol. The final acceptance and hope for the future is not discussed within the literature but this study reveals the participant’s perspective. Individual resilience directly links self-perception and how individuals contend with the impact. Shui et al. (2003) and Pound et al. (2005) accentuate anxiety and stigmatisation experienced with long-term medication which directly

influences identity and body-image. Literature does not specifically discuss self-perception and identity; thereby this study adds to this body of knowledge.

Warfarin initiation involved a grieving process for oneself. The researcher perceives that there is grief for a former life that they have now lost and can never attain again. Hence a need to work through the stages of denial, anger, bargaining, depression, and to finally accept (Kübler-Ross, 1970) that this medication is central to their ongoing health and well-being. As with any process, it is not necessary to go through all of these stages sequentially in order to reach acceptance and sometimes participants may become transfixed and never proceed to acceptance.

5.3.6 Lay pharmacology/beliefs.

Personal beliefs and values had a direct correlation to their concordance. Lay pharmacological beliefs were evident from all participants. Knowledge that Warfarin may be viewed as 'rat poison' confused and terrified some participants, whereas others disregarded this view. Although entrusting medication safety to health professionals, there was still knowledge deficits to its efficacy and mode of action both in humans and rodents. Ann acknowledges this "because you think about it being a poison and what effect it might have you know, whether it builds up I don't know". Warfarin is discussed by Webster et al. (2009) who acknowledge Warfarin is used as a 'rat poison' and a medication in humans, although trust followed. Safety was unquestioned because Warfarin was regarded as having being utilised in humans for a long-time. Webster et al. (2009) agrees that commonality in medication-taking alleviated concerns. My study agreed with current literature that regards participants' decisions surrounding medications as complex (Kumar, et al., 2011; Webster, et al., 2009), with socio-demographic factors nullified. Webster et al. (2009) also supports patients making value judgements regarding medication safety. Thereby this highlights medication safety as a social construct, with normalising and routines, which dismisses medication safety being regarded as only involving efficacy and side-effects.

Filtering of information and experiential knowledge enabled participants to disregard or educate others to deficits. Experience was complicated by external influences from others of fear and misinterpretation. Knowledge deficits were

occasionally filled by family and friends adding to beliefs and concerns. Hearsay did not affect decision-making regarding Warfarin because participants' experience empowered them to be experts in their ability. Cheryl explains how lay beliefs are universally applied; "Samuel can't understand why I have so many blood tests 'cos he says his friend doesn't...I said 'cos we're all different". My study disagrees that information deficits were filled by family and friends, increasing concerns and compounding their beliefs. Participants exhibited fortitude where their experience gave them knowledge, confidence, and empowerment to make their own conclusions.

5.3.7 Family.

Family was essential for support, with the shared-experience reducing isolation. Family encompassed spouse, siblings, children or caregiver. Family was an extension of 'self', with similar views and beliefs incorporated into management and monitoring. Warfarin therapy was experienced by 'significant others' as its effect resonated throughout their relationships. The support received was valued as a team approach, which reduced the isolation of taking this medication. Richard explains the teamwork that involves both himself and his wife; "well we're conscious we'll have to sort something out". Bajorek et al. (2007) discuss caregivers' opinions on Warfarin in the elderly, not the support and coalition that forms between family members in partnership that this study adds.

Family, from a Māori perspective is integrally linked to health and well-being. Family work together and care for each other. Family is not defined through European epistemology but Māori belief that family provides strength and encompasses past, present and future. Miriama reflects to her ancestors and the benefit of medical advancement; "You know our old people in our day, in our old days. If they only had all this help. I'm sure they would have mastered living longer". Māori participants were integrally linked to their family who provided and were actively involved in their healthcare. Connection to family supports literature which reveals the importance of whānau on Māori health (Durie, 1985; MoH, 2011a; Rochford, 2004). The need to ensure whānau is integrated to all aspects of PHC and health experiences for patients entwines family nursing whereby family is an extension of oneself and intrinsically linked. This supports families to divulge their

meaning (Hartrick & Lindsey, 1995) with open and respectful relationships empowering people (Hartick, 2000).

5.4 EDUCATION/KNOWLEDGE

ACQUISITION/INFORMATION-MISINFORMATION

Key components of education, knowledge acquisition and information are intrinsically linked and overlap. The majority of participants stated they felt underprepared with education, and although knowledge was acquired, it was not necessarily understood until it was experienced, or it may never be understood. Information they received was influenced by their beliefs. The internet was an information source all participants had accessed. Warfarin is commonly known as ‘rat poison’ and while fearful, participants were still compliant. Misinformation and ‘hearsay’ was obtained from others. Acquired knowledge did not necessitate understanding. A deep understanding was occasionally lacking, but the indication and need for Warfarin was understood. Participants with newly acquired knowledge verbalised increased difficulty than with those who had long-term experience. Experience was portrayed by increased complacency. The insidious nature of complacency became apparent the longer participants had been taking Warfarin.

5.4.1 Education.

Education was inconsistent, conflicting, confusing and generic. Educational experiences verbalised through discourse at interview highlighted the variance of educational programmes with differences in every institution, department and practice. Education was predominantly initiated in secondary care, and pre-operative stress increased feelings of inadequacy and reduced retention. Generic and group implementation reduced individualised needs of participants. Education occurred initially, but was not followed up or revisited which Sandra’s explains; “but I wasn’t well enough to...it was a group session before I had the operation, it was a video sort of thing” An ad hoc, generic approach is consistent with Geevasinga et al. (2004) findings. Bajorek et al. (2006) and Bajorek et al. (2009) qualitative research supports ineffectual education verbalised by all patients.

Memory issues were identified, although educational and literacy level of participants was not obtained. Estrada (2000) and Fang et al. (2009) suggest health literacy needs to target a person's cognitive ability, to ensure comprehension and understanding. Wilson et al. (2003) includes that culturally appropriate material is important. Analysis of educational material utilised was not possible with this study.

Educational deficits pertaining to diet, alcohol, medication and relationship of INR were recognised by participants. Although feeling underprepared and overwhelmed further information was not sought. Variance in educational requirements of individuals and the necessity for individualised teaching models and style was uncovered. Cognisance of variety in formats with consideration for participant's cognitive, literacy, cultural, educational and learning modes is essential. Richard explains his perception; "the lack of information, the lack of preparation...whether they've got a reason for not giving you as much as they could". Acknowledgement within literature identifies a requirement of increased availability of information with introduction of new medication (Barber, et al., 2004). Mazor et al. (2007) concurs with this study, that ongoing refresher sessions are required, but this does not eventuate in clinical practice.

5.4.2 Knowledge acquisition.

Knowledge acquisition did not necessarily transpose to understanding. The acquisition of knowledge is multi-layered and not attained by one educational session. Although health professionals had the knowledge required to educate, an aptitude was needed to communicate this in a style and language that correlated to an individual's cognition and requirements. Time was the measureable denominator to ascertain whether the knowledge had been acquired and is supported by Mazor et al. (2007).

The acquisition of knowledge is also achieved by the individual experience. Experiential knowledge encompasses self, impact, medication beliefs, priorities and time since commencement. Experience assists the formulation of knowledge after living, adapting and incorporating Warfarin into their life. Thus, the acquisition of knowledge is additionally achieved by the experience of individuals. Stack et al. (2008) supports the belief that medications are ranked in order of importance and if

there are significant and have perceived consequences, then adherence is more likely. These findings disagree with Pound et al. (2005) and Webster et al. (2009) who regard understanding and knowledge is required to make sense of medication as well as Dowell and Hudson (1997) where medication is stopped even with known fatal consequences. Experience was portrayed by increased complacency. The insidious nature of complacency became apparent the longer participants had been taking Warfarin.

5.4.3 Information/Misinformation.

The exposure to information was not always reliable and participants required an ability to filter and to be discerning. The bombardment and ease of access to information can be regarded as both beneficial and detrimental. Myths and hearsay added to anxiety and fear regarding medication, as well as participants' medication beliefs and values. The dichotomy was the misinformation regarding Warfarin as a 'poison' plus being prescribed to humans. Limited knowledge and understanding added to concerns attributed to scaremongering and rumours. Scaremongering and rumours did not deter participants from taking Warfarin, which Webster et al. (2011) agrees that knowing Warfarin was a toxic chemical was not a deterrent.

The internet was discussed by all participants and was frequently used as a source of information. Participants were discerning with information, although some blindly accepted what was read as truthful. Steve explains his thoughts "...so she fired into the internet and told me this and told me that...Well I think that that's so much bloody rubbish". There was a paucity of literature utilising this source of knowledge acquisition and Warfarin. My study highlights participants gathering information from a variety of sources, not only formal education sessions. Participants individualised the information to incorporate into their lives and interpret in their own position. Conflicting information was also regarded within this concept.

5.4.4 Individuals.

All participants are individuals requiring differing approaches. This study highlighted the individual variance participants exhibited in regard to acquisition of

knowledge. Variance places participants on a scale of requiring little information, to information in small segments, to absorbing every piece of information they could possibly obtain. Other participants wanted to experience how it felt in order to gain knowledge. Experience and knowledge is not explained by gender, age or educational level, although this is influential, but by personality and learning ability. There is a disconnection between the information imparted by health professionals or reading about it, and you experiencing Warfarin therapy that is different. Health professionals educate but conceptually they are unable to comprehend the experience of taking Warfarin on a participant's life. This study therefore uncovers that there is not a collective experience, but a series of individual experience.

5.5 HEALTH PROFESSIONALS

Relationships with health professionals were an integral part of Warfarin therapy. Relationships with health professionals and how this personally affects participants is through experience. Participants judged these relationships from an ability to trust, communicate and connect. In addition, the health professional's ability to be inclusive of a participant's perspective, work in partnership, and empower were essential.

5.5.1 Trust.

Respect and trust are integral to long-term relationships with health professionals. Participants highlighted that long-term relationships demonstrating trust and respect, increased their confidence. Pullon et al. (2011) corroborates trust as essential to patients and is perpetuated by regular contact and communication. Studies by Kerse et al. (2004); Kraetschmer et al. (2004); and Krupat et al. (2001) support trust enhancing a patient-centred approach, an essential component that reaffirms and reassures participants.

Participants tested health professionals and judged their ability by their ongoing relationship with them. Participants relinquished some control, in order to obtain expertise and knowledge from health professionals, which highlighted a power-differential. Participants' passivity diminished with long-term relationships

with health professionals as trust, knowledge and experience increased. As a result participants actively participated in decision-making by partnership. Ultimately, participants take responsibility for 'self', with guidance and assistance from health professionals. Participants' decision-making was considered and regardful to ascertain that they were in good health and maintain their personal safety. Kraetschmer et al. (2004) agrees and equates trust as not implying passivity. However, they regard participants who exhibit 'blind-trust' as more likely to be female, minimal education or over sixty-five years of age. This contradicts my study's findings having portrayed the experience of a diverse group of individuals.

5.5.2 Critical/mistrust.

Participants' experience sanctioned them to make judgements on the perceived quality of relationships with health professionals; which affected their ongoing participation with healthcare. The paternalistic attitude, poor communication and expectations extrapolated from secondary care experience saw some participants declining Warfarin initiation. Kraestchmer et al. (2004) substantiates congruence of beliefs between participants and health professionals incorporating power-sharing. Disempowerment in this context caused tension, mistrust and criticism. Advice was rejected until they could discuss with their trusted health professional.

Health professionals hold power as they are responsible for prescriptions and drug information. Participants filtered information through their experience pertaining to 'self, with increased support if health professionals were in unison with their values, expectations and beliefs. Stack et al. (2008) confirm that there was increased likelihood of medication adherence if consequences of not taking medication were increased. Dowell and Hudson (1997) disagree, noting patients were undeterred to stop medication, even with fatal consequences.

Neglect, inconsistency of ability, reduced care and attention experienced by participants heightened awareness of the incompetency and inability of skills and knowledge of health professionals. Mistrust was evident if participants' experienced concern regarding their own safety. Safety was regarded as a social construct, where normalcy and routines endorsed participants to make value judgements on the safety,

efficacy and side-effects of Warfarin of which Webster et al. (2009) concurs. Participants were concerned with their personal safety. Although not avoiding certain situations they were aware of the consequences of erratic INR recordings and side-effects relating to haemorrhage. If participants experienced concerns regarding their safety, they became mistrustful. Webster et al. (2009) disagrees, purporting safety did not concern toxicity and side-effects.

5.6 RELATIONSHIP WITH HEALTH PROFESSIONALS

Health professionals hold knowledge and it is their responsibility to impart this to patients. The involvement of an array of health professionals bombarded and confused participants. Conflicting education, advice and information often exacerbated this confusion. Health professionals designation was not verbalised which confused participants. Christine was unaware of who was educating her; “she was in the team”. Relationships that incorporate partnership, continuity of care and trust enhance participant’s experience. This is supported by the NZHCS (MoH, 2000) and the PHCS (MoH, 2001) where relationships promote inclusivity, equal power differentials, health equality and improved quality therefore empowering patients.

The researcher notes the challenge to health professionals involves the ability to communicate to a variety of cognitive and literacy levels, utilising individual learning styles and beliefs. It is the individual variance in ability, and desire to obtain knowledge that is challenging. Health professionals are required to adjust and vary clinical explanations to a level and depth unique to a participant’s requirements. Communication encompasses not only the ability to relate, but to impart knowledge and understanding at a deeper level to a variety of individuals, which encompasses a shift to a lay way of thinking. Kerse et al. (2004) and Kraetschmer et al. (2004) concur exemplary communication is required to ensure understanding.

Decision-making was delayed in secondary care in order to consult with PHC. Bajorek et al. (2009); Dantas et al. (2004) and Dudley (2001) support that individualised care is maintained through this approach. Dowell and Hudson (1997); Pound et al. (2005) and Webster et al. (2009) include allaying of concerns and

increased faith within this relationship. Pullon et al. (2011); Rodgers et al. (1997) and Toop (1998) confer partnership, shared-ownership, access and continuity of care as imperative components.

Participants had regular contact with a variety of health professionals. Participants' trusted a variety of health professionals to impart knowledge and look after their well-being, although their experience involved mostly doctors or pharmacists regarding drug information. The designation of health professionals was not always portrayed to participants. This incurs a 'blind-faith' to trust in some instances, but also a disregard to a brief encounter with a faceless organisation. Participants are pivotal in a cohesive team-approach, which fosters long-term relationships, continuity of care and a deeper level of partnership. Literature regarding relationships within PHC predominantly focuses on the doctor/physician-patient relationship. Literature emphasises the doctor as a leader, powerful and knowledgeable (Pound, et al., 2005; Pullon, et al., 2011). The literature highlights the lack of role for practice nurses within this contact and the invisibility of their roles in regard to Warfarin therapy; yet an untapped potential to develop this role within the PHC context remains (Geevasinga, et al., 2004; Lowthian, et al., 2011; K. Wright, 2010).

5.7 PRIMARY HEALTHCARE

Participants valued PHC and they found solace in long-term therapeutic relationships. Continuity of care, consistency, ease of access, advocacy and increased communication was provided by PHC. Primary Healthcare was pivotal in enhancing participants' experience. This included power-sharing, imparting knowledge at a level, depth and amount that is aligned with individuals' requirements. Achieving this is evidenced by an intuitive knowledge and history of a patient, originating from continuity, trust, communication and partnership. Geevasinga et al. (2004) endorse PHC having a substantial role with Warfarin therapy and recognise the exceptional attributes it has to deliver this service within the context of a patient-focused position.

Primary Healthcare's responsibility was increased with transfer of care from secondary services. Primary Healthcare lacked adequate recompense under existing funding streams as this requires increased services to patients. The use of funding initiatives to assist in increased time and financial outlay assist patients, but requires knowledge of Care Plus (2007b) and SIA (2007c) by PHC. These funding streams not only assist in increasing access for patients and utilisation of health professionals' time, skills and knowledge; but reduce their potential personal increase in financial outlay with Warfarin. By adequate recompense to practitioners for their time and services through funding initiatives, this absolves patients' from covering increased expenses personally. Some participants' experienced erratic communication of information, and inconsistency from secondary care services, as well as increased responsibility without adequate sharing of information. Some participants' experienced paternalistic, inadequate communication, anonymity, inconsistency and disempowerment from all secondary care facilities. Geevasinga et al. (2004) reveal inconsistencies through their study between primary-secondary care interface, which supports this study's findings.

Participants regarded doctors as visible, leaders and powerful as they had knowledge regarding medication. However, patients do participate in decision-making assisted by doctors. Literature regarding relationships within PHC predominantly focuses on the doctor-patient relationship (Dowell & Hudson, 1997; Krupat, et al., 2001). Carryer et al. (2007a); Pullon et al. (2011) and Toop (1998) corroborate collaborative teamwork can reduce burden in a complex, diverse population whereby partnership is fundamental. Nursing has the potential for development within this context.

5.7.1 Nursing.

Participants' experienced ongoing contact with nurses for Warfarin monitoring. However, utilisation, knowledge of delineation of roles and understanding of how this works in practice is negligible. Within a NZ context the management of Warfarin is based on individual practices, with allocation of nursing time for Warfarin monitoring increasingly disproportionate to doctors. Patients still regarded the doctors as knowledgeable and holding power, while nursing is viewed as ancillary. Bajorek et al. (2006); Geevasinga et al. (2004) and Wright (2010) agree.

Lowthian et al. (2009; 2011) acknowledge nursing roles are not well documented. Internationally, nurses' involvement in Warfarin therapy is diverse, from hospital clinics, nurse-led clinics to minimal involvement (Bajorek, et al., 2006; Fitzmaurice, et al., 2002; K. Wright, 2010).

Nurses working collaboratively; relationships that encourage shared-ownership are a tenet of PHC that represent the patients' perspective. In my opinion, although role definition is not comprehensively understood by patients, trust, exceptional communication, continuity of care, partnership, and shared-ownership are all exceptional qualities patients expect of nurses. Primary Healthcare nurses work holistically in long-term trusting relationships. Practising in a culturally safe manner epitomises the relationship nurses have in a PHC setting. Patients can verbalise participation and partnership, exhibited by empowerment and emancipation, not feelings of being demeaned or diminished (Nursing Council of New Zealand, 2011; Papps & Ramsden, 1996; Ramsden, 2000; Wood & Schwass, 1993). Literature agrees these traits are respected in PHC (Pullon, 2007; Pullon, et al., 2011; Toop, 1998) with patients respecting health professionals who have a patient-centred approach (Krupat, et al., 2001).

Nursing involvement and knowledge was found to be deficient. The ongoing contact nurses have with patients, the increased workload and time Warfarin therapy entails, sees PHC as pivotal, with opportunities to develop the role of nurses within this setting, which is supported by Geevasinga et al. (2004); Lowthian et al. (2009); Lowthian et al. (2011); and Wright (2010). The development of nursing involvement will require an attitudinal shift from doctors, patients and nurses in some practice settings. Participants' experience of nurses giving conflicting information would require increased education if role expansion was to occur. Ashworth and Thompson (2011); Kenealy et al. (2010) and Richardson and Gage (2010) support additional nursing education and role expansion. Nurses view doctors as managing Warfarin, with no role for nurses (Bajorek, et al., 2006). Contrary to this is the concept of nurses utilising standardised protocols (K. Wright, 2010). Bajorek et al. (2006) highlighted nurses' lack of knowledge and involvement in Warfarin which supports the disparity internationally regarding nursing utilisation and valuing role-development in this area.

5.8 LIMITATIONS AND STRENGTHS.

Utilising Guba and Lincoln (1985) criteria for assessing quality in qualitative research of trustworthiness, credibility, transferability, dependability and confirmability, the limitations and strengths of this study will now be discussed (Guba & Lincoln, 1981; Polit & Beck, 2006, 2008; Thomas, 2003, 2006; Topping, 2007).

5.8.1 Limitations of the study.

Deliberation on the limitations of this research requires an analysis of the approach. Credibility of this study was restricted through the small sample size and the word count of this thesis, which reduced the opportunity to richly portray individual participant's experience eloquently. The dependability and reliability of this study was confined through the inclusion and exclusion criteria. There was incomplete representation of all cultures as non-English speaking people were excluded. Dependability is constricted with replication of this study by demographic and geographical alterations. An inductive approach is deficient of philosophical underpinnings that traditional methodologies envelop. The researcher is inherently connected to inductive data analysis while another researcher could extract differing understanding and meaning, which reduces confirmability.

A small study as this potentially limits transferability. Transferability is synonymous with generalisability (Patton, 2002; Polit & Beck, 2008) which may be limited due to the small sample size. Reflexively, as a researcher I acknowledge that I am integrally part of the context and setting. Through self-reflection and awareness of personal bias, this assists in setting these aside. It is acknowledged that potentially the interview-guide may have led participants, rather than enabling them to uncover their experience. Less articulate participants were occasionally assisted in interview, which could limit portrayal of their perspective and introduce researcher bias.

5.8.2 Strengths of the study.

This study has significant strengths. Credibility was increased through explanation of the decision trail throughout the research. Returning transcripts to participants for validation; data immersion and manual data analysis by the

researcher increases confidence of staying true to the participant's experience. The researcher heightened the quality of this study by following ethical principles, obtaining informed consent, and ensuring confidentiality and anonymity of participants. Acknowledgement of individual experience does not reduce dependability of the data. Although small, this study reliably portrays a variety of experience. Through inductive analysis recurring themes were extrapolated from the data. An inductive approach facilitated the research findings to emerge from the data without the confinements imposed by structured methods. An inductive process ends after analysis of the data which cannot be set before commencement.

In order to increase confirmability interviews were audio-taped and transcribed by the researcher verbatim. After validation by participants the themes were manually extracted. Transcripts were analysed manually by the researcher. Two supervisors independently analysed 20% of the transcripts. Themes were discussed and agreed as representational. This study is powerful in that it has the potential to be transferable to other PHC settings through the rich descriptions of participants' experience. This fittingness allows application to other settings. The utilisation of excerpts from interviews also increases the authenticity. Reflection by the researcher acknowledges personal bias and culture as a nurse and recognition of their affect. Each interview was regarded by the researcher as a new experience. Each person was seen as an individual and encouraged to tell their story. This study has represented a diverse population, with a broad age range, and included most indicators for Warfarin therapy. Adding to current knowledge, this study discusses the effect of travel, the burden, discrimination and impact of obtaining insurances. It also identifies participant's experience was not collective but individual.

5.9 CONCLUSION

This study has been a small, inductive qualitative study. It has been the first to ascertain participants' experience within a community setting, utilising diversity of ages and variety of diagnoses. This study is the first to exclusively portray the participant's experience in PHC in NZ. Although recognising that PHC is not isolated as secondary care experiences overlap and were also discussed by participants.

Chapter five has discussed how Warfarin therapy impacts on participants' lives, and how this affects them is unique. The ability to normalise their life by routines and idiosyncrasies assists in reducing this impact and improves quality of life. The consequences of this medication increased concern. An inability to obtain insurances restricts choice and increases personal and financial burden on individuals and families. Reduced access and inequity to healthcare was experienced. Restrictions on diet, medication and alcohol affected choice which is socially restrictive. Travel increased personal burden and had significant financial implications overseas. Discrimination and prejudice by employers was perceived, although some employers were altruistic. Younger participants experience an increased encroachment to pursue an active lifestyle. Older participants had co-morbidities and poly-pharmacy which increased complexity of management.

'Self' resonates in all aspects of this study and participants' experience is the fundamental view. Although decisions may be restricted, the ability to make their own decisions, have control, responsibility and independence is empowering to participants. Externally their image does not appear different; it is the invisible internal tension that is personally apparent to participants. Alteration of self-perception changes participants, and an acceptance of a new image is integral. Māori health beliefs differ from the European culture and encompass a holistic stance that links all concepts to health and well-being. Māori utilise an adaptation of their traditional health perspectives with a Westernised approach to augment their health outcomes.

The commencement of long-term, complex medication like Warfarin can be accompanied by the grieving process for oneself. There is grief for a former life that they have now lost and can never regain. There is a need to work through the stages and to finally accept that this medication is essential. Lay beliefs and hearsay could either exacerbate anxiety or increase confidence, as experience developed.

Family was an extension of self. Māori perspectives to whānau (family) integrally linked them to their ancestors of past, present and future. Whānau is not a westernised definition of family, but embraces a wider context and community. 'Self' was an important component throughout this study.

Education, acquisition of knowledge and information was gathered in different formats by individuals. All was processed with regard to an individual's age, gender, personality, learning ability and educational level. Although information was ascertained, it did not necessitate understanding. Health professionals provide education, nevertheless, they are unable to understand deeply the experience; it is participants who are left to experience taking Warfarin. Experience assists in education, acquiring knowledge and information. There is not just one 'experience'; but the 'experience' of many people.

Participants had a variety of relationships with health professionals. There was a lack of clarity of the designation of the health professionals they encountered. Inherently trust, communication and continuity of care were important aspects of a basis for a relationship. Attributes of this relationship reaffirmed participant's ability to be active in their own healthcare. If aligned, then guidance was trusted which enhanced self-control and respect. If participant's experience was negative, this reflected in mistrust and criticism increasing their safety concerns. Primary Healthcare is pivotal with Warfarin therapy as it encompasses a position of improved access, trust, continuity of care, partnership and participation. Nursing roles are misunderstood and invisible with erratic ability and knowledge. There is the potential for role development of nurses within PHC. Role development will evolve through increased education and a shift from patients, doctors and nurses.

The limitations highlighted the reduced representation of a diverse population from differing cultures, non-English speaking and variances in communication. A qualitative inductive approach recognises that differing researchers may extrapolate different understanding and interpretation. The potential for researcher bias could have influenced this study with the researcher integrally linked to the research. However, reflexivity, awareness of personal bias, as well as participant validation were strengths. The next chapter will summarise this study and reference to the original aims. The implications for practice this study has elucidated will be highlighted, and Chapter six concludes with recommendations for further research.

CHAPTER 6

CONCLUSION

6.1 INTRODUCTION

This has been a small, qualitative study, within a community setting. The primary strength of this study is that it has been the first qualitative study, in PHC in NZ, solely to uncover the patient's experience of Warfarin therapy, involving a variety of ages and indications. There is a paucity of existing literature regarding Warfarin therapy utilising qualitative methodologies. A qualitative inductive approach appropriately gives a deeper insight and robust understanding into a participant's experience.

This research has enabled the patient's experience of Warfarin therapy to be highlighted, by attempting to produce an accurate unbiased perspective of patient's experience. The commitment of the researcher to this study was to endeavour not to misrepresent or misinterpret the participant's experience. The quality of this study was increased through the researcher's awareness and preservation of ethical principles and meticulous decision-making.

Chapter six concludes the research by discussing the impression the researcher had of Warfarin before the study was undertaken, followed by presentation of the key findings of this study. This will relate how the aims of this study have been achieved. The implications for practice for the patient and health professionals will then be conveyed, concluding with comments for future research.

6.2 IMPRESSION OF WARFARIN THERAPY

Working with patients who take Warfarin in PHC led to a questioning as to what their experience was. The initiation and development of this study originated from clinical practice through observation and conversation with patients on Warfarin. Warfarin therapy is mostly initiated in secondary care involving an unclear

transfer of information and devolution of responsibility to PHC. Patients were educated in secondary care, with education inadequate, generic and ad-hoc. In NZ, there are no specific national guidelines pertaining solely for the initiation, education and monitoring of people on Warfarin therapy (Geevasinga, Turner, & Mackie, 2004; New Zealand Guidelines Group (NZGG), 2003). Even though the Cardiovascular and Atrial fibrillation and Atrial flutter guidelines assist in recommendations for initiation and treatment (NZGG, 2003: 2005: 2009). The primary/secondary interface was not seamless as there were deficiencies in timely notification of information. Patients appeared overwhelmed, confused and felt vulnerable after initiation of Warfarin. Patients regarded PHC as trustworthy, secure and safe. Patients did not ask for help, even if unsure. Doctors made the decisions, however nurses allocated a considerable amount of time and energy into Warfarin therapy. There appeared anecdotally from the researcher's observations that there are a disproportionate number of Māori patients on Warfarin than non-Māori.

An inductive approach was utilised to facilitate expression of the patient's experience and point of view ensuring a robust understanding of the patient's experience developed. The inductive approach that underpins this research was based on Thomas' (2003) framework. An inductive approach utilised a less complicated and more efficient method of data analysis (Thomas, 2003). The identification of key themes emerged from data through inductive data analysis which illuminates themes rather than obscuring them. A qualitative inductive approach has enabled the research to explore Warfarin therapy, uncover and explore the patient's experience and the pertinent issues for them. Additionally, it also facilitates health professional's understanding of the impact on patients. Subsequently, this research has met the study's aims. The fulfilment of the aims is supported by the following summary of key findings.

6.3 KEY FINDINGS OF THIS STUDY

Six themes highlight the participant's experience. Firstly, the **impact** Warfarin has on participants' lives was revealed. Quality of life was attained through normalcy and adaptation of routines. Travel, although undertaken increased stress, financial outlay and dependence on health professionals as well as reduced

enjoyment. Concerns regarding travel, mortgage and health insurance as well as inequity of healthcare highlighted the increased personal burden and financial burden. Inequality in access to healthcare, discrimination, restricted choices and increased liability in obtaining mortgage, health and travel insurances were revealed. Lifestyle was restricted within social constructs, with Warfarin therapy influencing food, alcohol and any medication; complementary or conventional. Employment choices were perceived as altered and this potentially affected people financially. There was societal pressure and expectation to be employed. Self-employment gave increased autonomy. Some employers were supportive and understanding of medical conditions and the monitoring required with Warfarin. Increase in personal burden stimulated perceived discrimination, prejudice and increased apprehension regarding gaining or ongoing employment. Employment was integral to self-determination, self-worth, financial provision for family and enjoyment of life. Age affected participants in differing ways, although all were focused on the future and actively involved in decision-making. Longevity of life was apparent as age increased, and living a full life was evident when younger, although attitudes changed with increasing family responsibility. This theme met the aims by highlighting participants concerns and issues as well as their experience of Warfarin.

Secondly, ‘self’ involved actively participating and protecting oneself regarding Warfarin therapy through self-control, ownership and independence, while recognising expert advice. Self-control did not disregard personal safety which was evidenced by a clear understanding of the consequences of not taking Warfarin. The two Māori participants both endured CVD. The burden is supported by literature regarding the burden of CVD in the Māori population (Ajwani et al., 2003; NZGG, 2003). The relationship of Māori with health professionals was regarded within the context of their health belief, as an extension of family (whānau). Through incorporation of the principles of the Treaty of Waitangi, participants contributed and worked in partnership. The tenets of cultural safety were verbalised by participants by the transfer of power to them. This incorporated all participants and Māori belief into healthcare whereby they had control. Family is seen as an extension of ‘self’ which is supportive and a coalition. Family also relates to the Māori model of health that links health and well-being to family (whānau), and seeks strength in connections to family in the past, present and future. Warfarin is known

as ‘rat-poison’ and this was influential in myths and hearsay, increasing anxiety and stress. Participants became experts in their own ability whereby they could reach their own conclusions with knowledge, confidence and empowerment. The theme of ‘self’ converges the aims of patient’s beliefs with their experience.

Thirdly, **education** was ineffectual which equates with previous studies (Bajorek, et al., 2006; Bajorek, et al., 2009; Geevasinga, et al., 2004). Participants felt underprepared and overwhelmed. Education was initiated in secondary care and involved one education session, with no refresher or follow up sessions. There was no variance to individual requirements for teaching models or incorporating differences in learning styles, literacy levels, cognition or previous education. The individual experience highlights differing issues and behaviours which partially fulfils the aims.

Fourthly, **knowledge acquisition** is multi-layered and not achieved by one education session alone, but also by experiential knowledge. Health professionals have knowledge; however, this requires them to have an aptitude and superior communication skills to assist patients in acquiring knowledge. The aims have been implemented by accomplishing a discussion of issues for participants.

Fifthly, participants were bombarded with **information** that required them to filter and be discerning; the ease of access to information potentially exposes them to **misinformation**. Myths and hearsay added to scaremongering and rumours. Warfarin known as ‘rat poison’ incited fear and confusion amongst participants with a dichotomy of Warfarin being used to kill vermin versus its therapeutic use in humans. This theme complies with the aims by exposing the experience of participants as well as their concerns, issues and beliefs.

Finally, **relationships with health professionals** inclusive of partnership, continuity of care and trust improved participants’ experience. Communication was essential from health professionals and this included how they related and imparted knowledge. Confusion as to designation of health professionals reveals the inadequacies of engagement from secondary care services to participants. Primary Healthcare was valued, with doctors visible and regarded as holding power with

medication knowledge. Participants valued partnership and participation. There was regular contact with nurses, although their role and practice was invisible. There is potential for role development for nurses in regard to Warfarin therapy. Primary Healthcare was regarded as being trusted, allowing partnership, protection and participation. Power differentials were even, with participants involved fully in decision-making regarding their healthcare. Continuity of care, access and long-term relationships enhanced this. Communicating Warfarin therapy in a PHC context assists in fulfilment of the aims of this study.

The aims of this study have therefore been met with exploration of Warfarin. However, the aim of ensuring health professionals have an increased understanding of how Warfarin impacts on patient's lives will be met with the dissemination of the findings of this study. This will eventuate with publication of this thesis, and in an advanced nursing journal.

6.4 IMPLICATIONS FOR PRACTICE

This study adds to current literature and knowledge, in that it uncovers participants' experience. There are implications for participants and health professionals that can be extrapolated from these findings.

6.4.1 Implications for patients.

This study has assisted in making the patients' experience visible to reveal the impact Warfarin therapy has on their lives. Warfarin encroaches into all aspects of their lives and the repercussions reverberate in many aspects.

Although initial understanding and knowledge was gained through education, which was described as ineffectual, it was also accumulated through experience. Individual personal influences included beliefs, values, myths, hearsay and lay-pharmacological beliefs. Experiential knowledge is acquired through accumulation of information and experience. Patient's level of understanding and requirement for information is individual which necessitates an individualised approach accounting for level of ability, cognition, and style of learning. Māori health perspectives were evident and integration into healthcare is an important aspect. Integration of other

perspectives such as diversity of cultures, intellectually disabled, people who cannot verbally articulate, whether it is non-English speaking, or related to co-morbidities, will augment their experience.

Warfarin as a medication significantly affects personal burden and financial burden and this reverberates to numerous aspects of lives. Patients feel the effect of this with perceived discrimination and prejudice relating to employment opportunities. The ability to access secondary care services promptly is diminished with inability to gain health insurance. Delay in prompt access can potentially affect quality of life. Financially, insurance premiums are significantly increased and often unattainable which severely affects autonomy.

Information is attained through various mediums. Not all information is correct and appropriate. There is a need to filter and be discerning with information. Hearsay and myths resonate throughout the community and patients are exposed to these. These can cause increased anxiety and stress, but potentially complicate or endanger patients who take Warfarin. As 'experts' taking Warfarin, patients could educate others which could potentially be utilised in clinical practice. Warfarin requires an attitudinal shift for acceptance of this medication to normalise and assimilate into their lives. Warfarin encompasses a grieving process with patients' yearning a former time, to some form of an acceptance of medication. There is tension between external image of themselves, where Warfarin-taking is invisible to others, to their inner struggle knowing they are reliant on this medication and all it entails.

Primary Healthcare is valued and an important and pivotal component. Long-term relationships based on trust, ease of access and continuity of care assist in decision-making whereby patients feel empowered. Through collaboration with the PHC team, patients and health professionals work in partnership. This reaffirms that patients are central in PHC and are experts on themselves and their own ability. Participants became experts in their own ability whereby they could reach their own conclusions with knowledge, confidence and empowerment.

6.4.2 Implications for health professionals.

This study has highlighted aspects of practice where health professionals excel. There are however implications from this study that can be used to improve and support clinical practice. Health insurance, mortgage insurance, and travel have a far reaching impact on participants and need careful deliberation when considering health professionals are planning and implementing care. There are no specific national guidelines pertaining solely for the initiation, education and monitoring of people on Warfarin therapy, which increases the diversity of management. Education continues to be problematic and ineffectual for patients. Currently participants feel underprepared and overwhelmed on initiation of Warfarin therapy. Education needs to be individualised and reiterated. Patients may not ask for assistance, but refresher sessions may add to current knowledge and dissipate misinformation. Health practitioners need increasing awareness of diversity of learning styles and awareness of cultural diversity and using differing modalities in educational delivery. Health literacy needs consideration and the development of tools with cultural, intellectual and alternative learning modalities.

Awareness of individual values, beliefs and healthcare perspective is essential. Participants' health perspectives differ from the bio-medical model, and there needs to be cognisance that there is a diverse cultural representation within a NZ context, as well as other marginalised populations that are invisible. Incorporation of cultural and personal diversity into practice continues to be challenging with no supportive resource material. Individual practitioners are responsible for incorporating all of this holistically into practice.

The primary/secondary interface continues to be problematic and persistent motivation for a seamless transition will improve patient outcomes. The lack of clear communication and the disjointed service provision, the lack of clarity of information sharing and role-definition is potentially unsafe for patients and requires further development.

Primary Healthcare is valued and provides care that is trusted, easy to access, encompasses a partnership and has continuity. Primary Healthcare is valued by patients and needs to be nurtured. Patients valued working in partnership and having

an active involvement in decision-making which is empowering, although they still recognised the expert knowledge health professionals had.

Nurses have regular contact with patients, yet their work is invisible. The development of the nurse role could potentially develop further with nurses providing monitoring, education and management of Warfarin. Role development would require nurses to have increased education for this role. Correspondingly nursing advancement and involvement would increase their responsibility but potentially this may have a positive correlation to improving patient care.

6.5 FUTURE RESEARCH.

This research adds to the current body of knowledge, yet poses questions and eventualities for future research. Although highlighting the patient's experience further development is required to improve their experience and assist health professionals. There are no specific national guidelines pertaining solely for the initiation, education and monitoring of people on Warfarin therapy. Research to develop generic but individually applied guidelines could potentially enable patients to have a more streamlined approach to Warfarin initiation and management. Research piloting evaluation of educational resources, programmes and delivery warrant further analysis and would endeavour to ensure everyone was in concurrence. Research into health literacy is an area that requires development especially for people from differing cultures, non-English speaking, intellectually disabled or low/no literacy levels which could see the development of appropriate non-traditional educational resources. Research regarding the impact of insurances and work on patients would be worthy of consideration.

Incorporating families into health distinguishes different positions and ascertains the influence of utilising 'we' as an important aspect of the health experience, and not regarding patients as isolated individuals. Researching the family's experience would encapsulate and add to this research. Research comparing practice team approaches and experience with health professionals, patients and families would introduce a further dimension.

As a result of this research nurses could adopt new roles in education, management and monitoring of Warfarin. The principles learnt from education, management and monitoring could also be applied to other medications and practice, not just Warfarin therapy. The experience situates itself comfortably within a PHC nursing theory of knowledge and existence and encourages its usage within other areas of research. This research could feasibly be a catalyst toward instigation of further research for nursing within PHC.

6.6 CONCLUSION.

This research has made visible the patient's experience of Warfarin therapy. It has met the aims of this study utilising a qualitative inductive approach, by highlighting to patients and health professionals the encroachment this medication has on patients' lives and the impact that reverberates to all facets. Of benefit to patients and health professionals, this study values what is already working well, but also what could be improved. Although this study has added to current research, it recognises the fluidity of research and postulates areas that future research could take.

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Appendix A.

Warfarin Query Builder.

MedTech-32 Query Builder

Designer View | Data Sheet View

Query Name: Patients prescribed warfarin

Table: Patient

Fields:

- Name First Name
- Name Full Name
- Name Internal Name
- Name Preferred Name
- Name Previous Surname
- Name Surname
- Name Title
- Account Balance
- Account Date Last Invoice
- Account Date Last Payment
- Account Date Last Statement
- Account Group
- Account Group Description
- Account Holder (if one)
- Address Home Residence

Where:

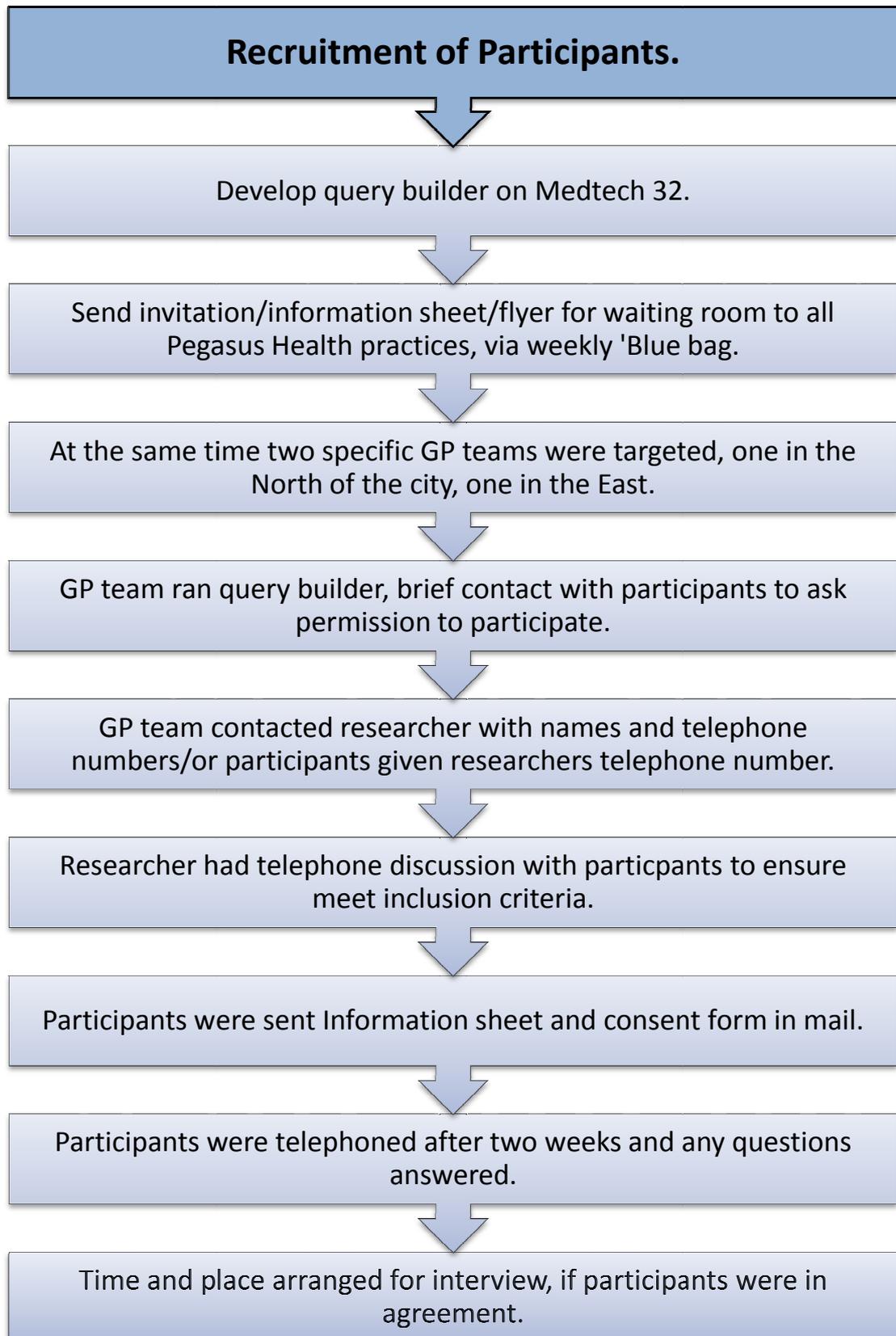
Column	Condition
Patient - Provider	Equal to
Patient - Registered	Equal to Registered (R)
Prescriptions - Date of Prescription	Between Tue 15 Jun 2010 00:00:00 and Fri 22 Oct 2010
Prescriptions - Drug - Code	Equal to Warfarin Sodium 1mg Tab

Select:

- Patient - Name Title
- Patient - Name Surname
- Patient - Name First Name
- Patient - Dob - Age
- Patient - Gender
- Patient - Phone - Home
- Patient - Phone - Cell

Buttons: Run Query, Run SQL Query, View SQL, Close, Help

Appendix B.



Appendix C.



Information Sheet.

Title: The experience of patients taking Warfarin in Primary Care.

Introduction: You are invited to take part in a study that asks you to talk about what it is like for you taking Warfarin every day. You are asked to think about this in the next two weeks, before deciding to take part.

Participation: Your taking part is entirely your choice. If you choose not to take part, you will still receive the same care and treatment you have had before.

If you agree to take part in this study, you are free to withdraw from the study at any time. You do not need to give a reason for withdrawing.

Being involved in this study will be stopped if you or your doctor feels it is not in your best interests to continue.

About the study:

This study aims to look at people taking Warfarin in General Practice and allow them to tell their story of how it is to live with taking Warfarin daily. This will include what your concerns, issues, beliefs and behaviour towards Warfarin is. A lot of research looks at Warfarin from a medical view. This research will uncover a patient's perspectives.

There will be up to 10 people involved in this study. They will be selected by asking GP's from Pegasus Health, to nominate patients who take the medication Warfarin. The researcher will invite people who take Warfarin to participate. The study will include a mixture of ages, men and women and areas people live.

Once enough information has been gathered, recruitment will stop. The study will take place in Christchurch, either in participant's homes or at Ferry Road Medical Centre. Participating in this study will take approximately 1 hour of your time.

This will involve you being interviewed by the principal researcher, while telling your perspective of what it is like to take Warfarin long-term and the impact this has on your life. The interview will be audio-taped and some notes will be taken by the researcher at the same time. Once the interview has been transcribed, it is able to be returned to you, if you want to, so you can read over it and confirm if you are happy with the content. You have the right to delete or alter the transcript at this time.

Benefits, risks and safety.

This study aims to highlight and provide insight into issues, concerns and behaviours to Warfarin in order to assist with education, and management of this medication. Previous research has not looked at patient's viewpoint. By undertaking this research, it is hoped that there will be a strengthening of the partnership between patients and health professionals in primary care and assist in patient participation in their ongoing healthcare.

This study involves you discussing Warfarin with the researcher. The researcher will either come to your home, or you can go to Ferry Road Medical Centre to be interviewed. This would involve you

arranging your own transportation to get to the medical centre. It is not thought that there would be any known risks involved in this interview.

To be included into this study you will need to be a registered patient in a Pegasus Health practice. You will need to be taking the medication Warfarin, long-term and have been taking the medication for longer than 3 months. If you are under 18 years old and/or have your Warfarin monitored by Christchurch Public Hospital or somewhere that is not your GP, you will not be able to participate in this study.

General.

If you want any further information about this study, you can contact the principal researcher at the address or telephone number provided.

You may have a friend, family or whanau support to help you understand this study and to discuss if you do or do not want to participate, or any other explanation you require.

During the interview, you do not have to answer all the questions and you may stop the interview at any time.

If you have any queries or concerns regarding your rights as a participant of this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

Confidentiality.

No material that could personally identify you will be used in any reports of this study. A different first name will be used to identify you. This will be totally different to your actual first name. You can agree to this name if you wish. Only the first and second supervisor will have access to the data records.

A copy of the transcripts and the audiotape is kept securely locked for 10 years. Computers will be securely locked with passwords. Initials or a code will be used so you cannot be recognised or able to be identified.

Results.

If you would like a copy of the research results, these can be sent to you. Either as a summarised copy or you can request to be notified of which publication the results could be found. There will be a delay from when you are interviewed and when the results are published.

Alternatively the principal researcher is happy to make an individual appointment with you to discuss the outcomes of the research.

Statement of approval.

This study has received ethical approval from the Upper South A, Ethics Committee, ethics reference number: URA 10/07/046.

Please feel free to contact the researcher if you have any questions about this study.

Principal Investigator.

Gillian Currie.

Student Researcher.

Ferry Road Medical Centre.

276 Ferry Road.

Christchurch.
Telephone: 381-0551.

Supervisor.

Dr Patricia Maybee.
Senior Lecturer.
Centre for Postgraduate Nursing Studies,
University of Otago,
Christchurch.
Telephone: 364-3850.

Patient Advocacy Services.
Christchurch Public Hospital.
Telephone: (03) 377 – 7501.

This is free and is independent of any health professionals.

Appendix D.



What is it like for YOU taking Warfarin long-term?

- I am seeking to interview patients taking Warfarin long-term.
- I am interested in what it is like for you.
- This is an opportunity for you to tell your story.
- How do you manage?
- What are your concerns?

This research is being conducted as part of a Masters of Health Science-Nursing.

This research has ethics approval from the Upper South A Ethics Committee.

INTERESTED?

Want more information?

Then contact:-

Principal researcher: Gillian Currie.

Telephone: 027 379 0017.

Time commitment: One hour.

Where: In your own home or Ferry Road Medical Centre. You choose.

Appendix E.



Consent Form.

The experience of patients taking Warfarin in Primary Care.

This study is about your story. What it is like for you taking Warfarin; your beliefs, concerns, issues and ways in which you take Warfarin.

	Yes	No
I have read and I understand the information sheet dated 26 th July, 2010, for volunteers to take part in the study, to look at my taking Warfarin.	<input type="checkbox"/>	<input type="checkbox"/>
I have had the opportunity to discuss this study.	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with the answers I have been given.	<input type="checkbox"/>	<input type="checkbox"/>
I have been able to use whanau support, or a friend, to help me ask questions and understand the study.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that taking part in this study is my choice, and that I can withdraw from the study at any time, and this will in no way affect my future and continuing healthcare.	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	No
I understand that my participation in this study is confidential and	<input type="checkbox"/>	<input type="checkbox"/>

that no material that could identify me will be used in any reports on this study.

I understand that the interview will be stopped if I am not comfortable with continuing.

I have had time to consider whether to take part in the study.

I know who to contact if I want to talk to anyone after the study (See patient advocacy on information sheet).

I consent to my interview being audio-taped.

I would like the researcher to discuss the outcome of the study with me.

I hereby consent to take part in this study.

Name of participant:

Signature:

Date:

Full name of researcher:

Contact phone number for researchers:

Project explained by:

Project Role

Signature:

Date:

Appendix F.

Interview guide.

- Welcome.
- Thank for participating.
- Ensure consent/ right to withdraw at any time.
- Written consent- post copy back.
- Right to cease interviewing if desires.
- Invite participant to give background to **why** they take the medication Warfarin, how long they have been taking it and their relevant medical history. What other meds taking?
- What their **knowledge** is about the medication:-
 - What is it for?
 - How it works.
 - When to take.
 - Monitoring.
 - Interactions with food, drugs.
 - Problems.
 - Side effects.
 - Hospitalisations.
- What **education** did they have when started Warfarin.
- How does it **affect their life**. Impact.
Interfere?

Adjustments?

Significant?

- **Back at beginning** of starting Warfarin what would you like to have been advised of?
- **Work** – adjustments, time off work, how manage.
- **Concerns** about the medication.
- **Beliefs.**
- **Behaviours.**
- Family/lifestyle.
- Feelings related to Warfarin.
- Other issues they feel relevant.
- Money concerns.
- Forget to take?
- Thank for their time.

Return transcripts for validation. Copy of results of research findings/ where research finding published.